

February 2020 account of my treatment for Mesothelioma after 18th months of treatment so far.

Since my diagnosis in July 2018 I have had various treatments and offers of clinical trials. It seemed the Macmillan nurses at the Queens Hospital, Burton wanted to “fast track” me onto the MARS2 trial at the Glenfield Hospital Leicester. But after meeting the surgeon for the randomised trial and reading the 10 page summary of what was involved, I and my family decided it was not for me. We thought it too risky and offering a very poor quality of life if the operation was carried out and it would not get rid of the cancer. This was confirmed recently by my current Oncologist who confirmed that few people live for any length of time after this operation and suffer a poor quality of life.

I decided to go for the NHS treatment of Chemotherapy, and after seeing the Oncologist at the Royal Derby Hospital, I was started on Pemetrexed and Cisplatin Intravenous drips of 8 pints of various fluids over about 7.5 hours, while connected to a pump. I had 6 sessions of this at three weekly intervals with some CT scans. The first scan showed a remarkable cancer reduction in size from 27mm down to 5mm, but the second scan showed the cancer was still progressing having mutated to become resistant to the drugs. This treatment was an ordeal, both mental and physical with all the side effects of the drug making a normal life very difficult to get on with and even disrupting normal family communications, and the end result was very disappointing after all I had put my body through.

After more meetings of the Joint Multidiscipline Team, to see which the best way was forward for me, I was offered a trial drug at the Leicester Royal Infirmary, if I was suitable. After a meeting at Glenfield Hospital, to fill in forms and my biopsy sample from the Queens Hospital Burton then being checked for suitability, I was told I was suitable for three trials which they were conducting. In May I started on the MiST trial (Mesothelioma Stratified Therapy) taking Rucaparib oral chemotherapy tablets. This was successful for a start but in late June my white cells were also being depleted and I had neutropenic sepsis as a result. This resulted in having to be taken to A&E at the Good Hope Hospital for 5 days as an in-patient in a solitary room, being treated to build up my white blood cells and then having a reduced dose of the drug Rucaparib. This reduced dose did not work so well and the cancer was again found to be progressing. As a result I was taken off the trial. I was offered another trial at the Leicester Royal Infirmary, but this was randomised and could mean I would have the placebo, which in my opinion would not benefit me at all.

As my condition was related to my working environment in the 1965-1981 period, my solicitor secured an agreement that as part of a compensation package, that I could have an Immunotherapy drug which they would pay for, so on 15th November 2019 I started having the drug Pembrolizumab, (brand name Keytruda) and up to the end of 2019 I had had 3 sessions with no side effects.

Wednesday 1st January. Another day, another month, another year, another decade which I was not expecting to reach, for the forecasts I was given by the medics were very gloomy and I feel that these predictions were based on out of date information, considering the advance of medical treatment for this condition. I had to take a pain killer for my back pain which seems to be getting worse, I can tolerate it but it is better when I take a couple of Co-codamol tablets from the chemist.

We had restful day and Justin rang to wish us happy New Year. After having some more beef for dinner we watched TV until nearly midnight.

Thursday 2nd. Had my Weetabix and that did me until dinner at 3pm - roast beef, cabbage, roast potatoes. I did not seem to have an appetite today. I had a nice bath at noon which made me feel better, but both Ann and I were very tired and devoid of any energy today. We watched TV after dinner. I had to take a pain killer for my back pain.

Friday 3rd. I took my usual morning tablets for blood pressure and had some Shredded Wheat and cornflakes for breakfast. I did Ann a ham sandwich and some pork pie and had some pork pie myself. As it was nice and sunny outside I went and did the new stickers on the green bins for them to be emptied in 2020. I did a bit of cutting some branches off the apple tree for the bin and set 21 broad bean seeds in the soil in the greenhouse. We had a chicken pie with some chips and peas for dinner with a strawberry cheesecake for afters. We then watched TV.

Saturday 4th. We went shopping at Morrison's and read the papers when we had put it away. I got the boxes from the room above the garage to put the Christmas decorations in and we started to take them down and put back in the storage boxes. This took us about 3 hours and when all finished I struggled with them to go back above the garage but managed it. Will they be needed next year? We then had a rest and later got the dinner ready of fresh salmon, runner beans and potatoes. We washed the pots and then sat down to watch TV and listen to the football commentary on the radio.

Sunday 5th. I got an early start on some of the things in the garden which wanted disposing of in the black bin and got it ready out the front for the bin men tomorrow. Ann wanted a ham sandwich with some pork pie for breakfast so I made this for her and we had a cup of tea with it. We then made a beef casserole with the diced beef we had purchased yesterday and got this in the oven for 11.30am to cook. After a few weeks of having a pain in my back, which has been gradually getting more painful daily, for some reason this morning it appears to have gone.

Monday 6th. We stripped the bed and started on doing the washing. We were tired today and my back was very painful enough for me to take to Co-codamol tablets after dinner at 4pm. We watched the TV at night for the Cup draw and the live match.

Tuesday 7th. Jane did not come today as she has been in hospital until 4am and has to go back later. Age UK rang with this message and tried to arrange for someone else to come but as we have to go to the hospital this afternoon, they will come tomorrow morning at 9.30am instead. We went to Good Hope Hospital and Ann saw Dr Henderson the Breast Cancer Consultant Oncologist. She was weighed beforehand and told she had lost a bit of weight; this is probably because she is a bit more active now. Dr Henderson asked how she was and she said she was feeling quite good and he was pleased with this. We got to the hospital early and saw the Dr before appointment time and managed to get home for 2.30pm. We put the beef casserole into the oven and had some of this with mash, carrots and sprouts. We watched the football on TV at night.

Wednesday 8th. Tamzin came and did the ironing and also the washing up to fill in her 2 hours. Ann had a bath before Tracy came to do her hair. We then had a rest in the armchairs before getting the dinner and finishing off the beef casserole. We watched the football at night. Justin rang and

mentioned him taking us to M&S one Sunday in the next few weeks and then having dinner at his house and seeing the children.

Thursday 6th. We had breakfast - a ham sandwich for Ann and a shared pork pie. We then got ready and went to the Odeon to see the Aeronauts film. We then had a dinner in the Bolebridge which was not very nice and went into Ankerside for Ann to get some birthday cards and me to sort out the hearing aid people. We came home and rested, watching some TV and using the computers.

Friday 10th. I went to get the car out this morning to take Ann to Good Hope Hospital and noticed a pile of soil and turf at the bottom of the drive. Some B@**@*! must have turned a lorry opposite our drive and in it and drove forward taking a lot of the side bank with it. I tidied it up when we got back and will ask Reas to have a look at it on Monday when he comes to jet wash the drive and patio etc. Ann saw the haematologist this morning and he is very pleased with how she is doing. He wants her to keep doing a bit mobility wise which will help her and not to overdo it. I think how we are both doing mobility wise at present suffices for this. He weighed her before going into the clinic and this was to decide the dose of tablets he gave her to take instead of her having the injections in her tummy for the Pulmonary Embolism, 1 tablet per day for life along with all the other stuff she has to take. He is that satisfied with how she is doing that he has discharged her and will not want to see her again but gave her the phone number of his secretary should she need to contact him again. We went to the pharmacy to get her tablets on the way to the treatment room where she had another blood sample taken so they will know how her blood is next Tuesday when we go again. We got a fish and half a cone of chips and small peas on the way home from Belgrave for dinner. We spent the rest of the day relaxing and watched the football match on TV at night.

Saturday 11th. We did the shopping and had a beef slice for breakfast purchased at Morrison's. We both felt very tired and read the papers we had brought until it was time to cook the salmon for dinner. After washing up we watched TV football, Liverpool V Spurs.

Sunday 12th. Justin came up on his own and watered the plants and told us details of going to his house next Sunday for dinner after a visit to M&S. We cooked the joint of beef we purchased yesterday and had roast potatoes, runner beans, parsnips, Yorkshire and gravy which were delicious. We then watched the match on TV and the programmes afterwards.

Monday 13th. Reas came and did the pressure washing of the patio and the drive etc. I went into town to see the asthma nurse and she was pleased with me and she got her husband Mark to give me a prescription for some strong pain killers for my Cancer versus Keytruda battle which is giving me some pain and discomfort. We had the roast beef with parsnips and cauliflower today and it was great. I made Ann an appointment to see Dr. White on Thursday.

Tuesday 14th. Jayne from Age UK came and did the housework; she is much better and still waiting on the medics to sort her out properly. Ann went to Good Hope Hospital and her blood was OK so she had the injection and another supply of Immunotherapy. We came home and I got the dinner and we then watched TV until Justin, Emily, James and Bethany came to see us and they all had a big bunch of flowers for Ann's Birthday.

Wednesday 15th. After Ann having her hair done and us having some breakfast, we went to Good Hope Hospital and I saw Dr Baijal who was pleased with me and arranged a blood sample and to see me again on 5th February. We got the dinner when at home and then watched TV and rested.

Thursday 16th. Ann had got an appointment to see the doctor at 9.50am to review her medication and to get it all available on repeat prescriptions. The ones due now were obtained from Rowlands pharmacy after he had sent it across electronically. We then had a drink and something to eat in Greggs before going up to the Odeon to see "1917". It was raining when we came out so we returned home and I put two potatoes in the oven to have with the cauliflower and beef. Despite me trying to go to the loo, I could not do anything and my tummy was very painful and bloated, so I took another Movicol powder and did not have anything to eat and drink for the rest of the night. A nurse called Gayle called to say she would be coming about noon time to give me the Keytruda tomorrow.

Friday 17th. I did manage to do some poo at 2.30am and then again at 9.45am after having some cereal. My tummy is again feeling bloated and wanting to poo after all this, but I just stuck to a cup of tea while the nurse was due. The Nurse came at 12.15 and got all her stuff out and put the cannula into my right hand 1st time. At 12.35 I was connected to the drip. First it is Saline to fill the tubes, then Keytruda for 30 minutes and then Saline again to purge all Keytruda into me. Job done at 13.40 and Gayle started to pack up her stuff and remove the Cannula. While she was here, Gayle informed me when I asked about Keytruda, that she has a patient she is treating with Keytruda and he has been on it for over 2 years with no ill effects. I also told her that Ann was taking Ibrance for her cancer and she said she has a lady patient who has been taking this for over 3 years now and is well, she just gets tired from having it like Ann and I do. She told me not to suffer any pain and keep taking the painkiller even though since I started then I have had very bad constipation. Keep taking the painkillers and the laxatives I have and try to get a balanced medium with taking them both.

Saturday 18th. We did the shopping and after putting it away had a hot cross bun toasted and buttered and read the papers. I got a small tree up from the front garden which is half dead and put this and some fallen broken branches from the winds into the black bin and put it out of the front gate for collection. We then had the salmon with beans and potatoes for dinner and watched TV for the rest of the night.

Sunday 19th. Justin picked us up at 9.54am and took us down to M&S to do a bit of shopping, and then back to his house to see James and Bethany. Emily was cooking a nice steak pie dinner which we all had and enjoyed and a lemon tart for pudding. We were playing a game when my stomach started to ache and I had to go to the toilet, which unfortunately lasted for over half an hour as I had over done the bran etc. I had to go again a few minutes after the first time for another 20mins or so until my bowel emptied. We then stayed for another hour with me feeling better before coming home at 4pm. I got better cleaned up and changed my clothes and we watched TV for the rest of the night.

Monday 20th. We just have a buttered hot cross bun for breakfast with a cup of tea, and Ann put the washing machine on to wash the sheets etc. after we had changed the bed linen. We had a lasagne for dinner and rested watching TV the rest of the night.

Tuesday 21st. Ann had some salmon left over from Saturday for breakfast and I stuck to cereals. Jane came at 9.20am and did the ironing and fitted the duvet into the cover which had been washed and

ironed. After she had gone just before noon, we prepared the steak and got the vegetables ready. We then had a bath each and shampooed our hairs. Ann had her hair done and when Tracy left we put the veg on to cook and had a very nice dinner. After washing the pots up we went in to see the TV.

Wednesday 22nd. The district nurse came to see how I was coping in the morning and was very pleased with me. I let her read the booklet of my treatment filled in by the Healthcare at Home Nurses on each visit to me and she was very satisfied and congratulated me on getting this treatment privately as she knew what a struggle I had had to things moving with my treatment. I told her of my trouble with constipation which the healthcare at home nurse said could be caused by the Solpadol 30mg/500mg painkillers I am taking, she suggested seeing the GP for some laxatives but I am already having laxative foods (Weetabix, Shredded Wheat, Bran flakes etc.) as well as Movicol Powders, Fibogel and Lactulose, which are largely having no effect on me going to the loo. We had the steak with some mash, carrots and Sweetheart cabbage and it was delicious, and then rested and watched TV at night.

Thursday 23rd. We went down into Tamworth for Ann to get Lucy a present for her birthday. As we enjoyed last Thursdays trip so much we again went in Greggs and had a sausage roll and tea for Ann and a Bacon bap for me with an orange drink. We then went to the Odeon to see "Official Secrets" on the senior screen and after did a bit more looking at the shops for Lucy's present before going into Weatherspoon's for a small scampi and chips each with a half of Shandy for Ann and a half of Guinness for me. We came home and rested watching TV after reading the newspapers we had got in Tamworth.

Friday 24th. I cleaned and de scaled the iron of internal debris as it had not been done for months. After reading the "Tamworth Herald" I started to prepare the vegetables for dinner. I had to top up the potato storage vessel in the house with the last of the potatoes I had grown in our garden last year, so these will have lasted until late February at least at current consumption. We had the dinner and rested watching the news before washing up the dinner pots. Ann then did the shopping list for tomorrow whilst I updated this account.

Saturday 25th. We did the shopping at Morrison's and had a meat pasty when we had put it away. We then read the papers and settled down to watch the FA cup match starting at 1.45pm. We had some fresh salmon for dinner and watched some TV and did some reading of a book which was a Christmas present.

Sunday 26th. Justin came up and watered Ann's plants and I did the blue bins ready for the bin men tomorrow. We had the rest of the salmon for dinner same as yesterday and then watched the cup matches on TV and the last of the Trial of Christine Keeler.

Monday 27th. We went down into Ankerside after Ann returned and got some more trousers from the Co-Op. We then had a sausage roll and drink in Greggs before going to the Odeon to see the David Copperfield film. We then had a light dinner in Wetherspoons before coming home to rest for the night.

Tuesday 28th. Jayne came and did the house work and Pete came to do the T5 lawn treatment. We then had the loin of pork for dinner with beans, carrots and mash which was very nice. We then saw

the Carabao cup semi-final which Leicester lost to Aston Villa. Our Joan rang and I could not understand a word of what she said so got Pauline to explain things.

Wednesday 29th. Tracy was ill so could not do Ann's hair and will come tomorrow. The foot lady came about 2pm and did Ann's feet and she had not received a referral for the doctor to do mine. We had dinner as yesterday and watched TV at night.

Thursday 30th. Tracy came and did Ann's hair after we had both had a bath. We then went into town and had the usual in Greggs and then to the Odeon to see "Little Women". We had a light bite in Wetherspoons and came home to rest at night. My pain in the left side back had now got to the state it is not being relieved by painkillers and is there all day and night.

Friday 31st. We stayed in and rested, reading a book and then getting a dinner with the rest of the pork loin. We watched TV at night.

Saturday 1st February. Another month, another milestone. We did the shopping at Morrison's and then I cooked us a breakfast of sausages, mushrooms, hash Brown and fried bread. We then read the papers and Ann listened to the Leicester V Chelsea match on the radio. Justin popped in with James on the way to have their hairs cut and make arrangements for tomorrow. We watched the football updates on TV and at 4pm I cooked the fresh salmon with green beans and potatoes. We then watched the live match on TV. I had a letter from Good Hope Hospital asking me to attend for a CT scan on 25th February at 5pm.

Sunday 2nd. Justin picked us up at 10.30am to take us to his house to see the grandchildren and have a Sunday roast Emily was cooking. We had a nice meal and some playtime with James and Bethany, before coming home about 4pm. We were both in good health today apart from the constant pain I keep having in my lower back around the waist area. We watched the football on TV at night and rested. I finished watching the Video 1968 which Justin had bought me for Christmas.