

Nuking the Teabag

The Story of my Prostate Cancer Treatment.

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In July 2017 after a routine trip to the doctor's, I was diagnosed as having stage 2/3 prostate cancer which was not curable by surgery. I therefore went through a process of radiotherapy at Southampton Hospital and appear to have come through it successfully.

None of the classic symptoms had shown up beforehand.

This is the story of that treatment.

A Haemorrhoid, a Remote Island and a Music Festival

It all started in mid July 2017. I was looking forward to a week on Lundy, a small island off the Devon coast with limited facilities, particularly medical. I'd developed a nasty haemorrhoid and to cap this, a week after I was due to return from Lundy, I was going to the Boomtown festival – more days living rough with dubious facilities. To make sure the thing wasn't going to turn into anything that could become nasty while living in such an environment, I made a quickie appointment with my GP to get the haemorrhoid checked out. Two days later in the GP's surgery, lying sideways on his couch, trousers down and bottom-half all naked, he pronounced the said protuberance to be quite a large one, but perfectly safe. "I'd just have to live with it, it would go away eventually, creams might help soothe things". Then he says, "While you're there, I'll just take a routine look at your prostate". 'Hmmmphh...', thinks I, "here we go again".

I'd been through this ignominy twice before so just lay back and thought of England while he lubricated his nitrile gloved finger and got down to the task. Previously, at a private medical examination, the Doctor then had commented that some people pay money for this act. No such comments on the NHS though. After a bit his face took on a thoughtful look and he uttered the not-too-encouraging words, "... your prostate isn't over-enlarged, but it feels a bit unusual and I'm not sure about it. I want to do a PSA test to make sure".

Now, my father had had an enlarged prostate at the age of 50, several years younger than I am now; PSA tests weren't around then so he had had nothing done about it yet lived another 30 years. However, the classical physical signs of an enlarged prostate had shown up with him although they clearly were not too troublesome and he tended not to discuss such matters anyway. In my case there were no classic symptoms at all – in other words pee flow seemed normal and I perhaps got up once in the middle of the night, perhaps two days out of three. Hardly unusual. There had been a couple of flow-start issues perhaps once or twice that I put down to other reasons, like taking Sudafed for a cold a year previously; a medicine that does cause problems in that area. The GP had said my prostate wasn't enlarged, so perhaps it wasn't too surprising there were no problems.

A blood test was booked at the surgery for two days after I returned from Lundy and I more or less forgot about the issue. The haemorrhoid hadn't been a problem while on the island, with very little discomfort – so we shall hear no more of that. I dutifully went along for the PSA blood test then spent four rather surreal and very pleasant days at Boomtown (with no psychotic drugs being consumed apart from diluted ethanol!) On one late night trip to the posh flushing loos (accessible only to those of us paying exorbitant prices for accommodation packages; everyone else had to suffer compost loos) I did once have a problem getting flow started. But walking around outdoors among the tipis and accommodation huts at 03:00 in a thin dressing gown could probably do that anyway – so I put it to the back of my mind; it happened just the once.

A day or two after coming back, while still in a slightly surreal state of mind a letter dropped through the door saying I needed a hospital appointment with a uro-oncologist, and that I needed to contact the surgery to arrange things. Err.... 'ang on. This doesn't sound good. That same day there was also a phone message recorded on the answering machine from my GP. I rang the surgery and they said he would ring me later that day. Now I really was beginning to get quite a bit worried – GPs surely don't make this effort to contact you if it's not serious. The phone call came and sure enough he said my PSA level was elevated but the phone call was mainly to relieve fears about the wording in the letter: "... it may not be anything serious –but 'uro-oncology' is still not what one wants to hear, is it "!

After a bit of pressing I was told my PSA level was 13. Googling 'PSA levels' informed me anything less than four was normal, but that serious prostate cancers can lead to values in the hundreds. So I was slightly reassured at that point, such is the power of the Internet. Also by the fact that a friend who had recently had his non-aggressive but greatly enlarged one chopped out had originally had a PSA of 16. Visiting the surgery next day, the process was all set in motion, I would get an appointment at Southampton General Hospital within the statutory three weeks mandated for cancer diagnoses. I was offered the option of having treatment at Portsmouth instead. In spite of being a bit further away, travel there would be easier than to Southampton. However, the reputation of the Portsmouth Queen Alexandra went before it and there was no way I would even consider that option!

More Lubricated Fingers, and it starts

An appointment letter finally arrived for 31st August, just one day short of the statutory timeframe – they'd met the three week limit, so that was their box ticked. I'd rarely been to Southampton General before – just one trip to A+E to get checked out after a fall when I'd turned up very early in the morning, so had no opportunity to see the car parking problems that occur later in the day. This appointment was for 10:00 but as I always leave huge timing margins when visiting strange places, set off from home, driving, at 08:00. Needless to say, since we were still in the school holiday period I managed the 8.5 mile journey in less than half an hour. Car parking, which I didn't yet know was normally an absolute nightmare at this hospital, proved to be straightforward in the main multi-storey at that time in the morning. The instructions in the appointment letter were quite clear about the destination so I spent the spare hour just walking round the hospital site – a veritable hotchpotch of building site and disorganised road layout. Eventually, I found myself in the waiting room for the Uro-Oncology clinic. Apparently they had two clinics running in parallel, no doubt in order to meet the three week timeframe for all their customers.

Almost bang on time the consultant came up and introduced himself, then asked if I wouldn't mind a female medical student sitting in as part of her training. "Whatever", says I, "no problem". The consultation started off with the student taking me off to a side room and asking the standard set of questions relating to pee flow rate and frequency, and how many times I got up in the night. Almost exactly the same set of questions I'd been asked before by my GP. After a short delay I was called into the consultant's room, along with the student. He explained the significance of the high PSA level and that they had to work out why it was high. Then the inevitable; onto the couch, trousers and pants down, lie on my side, same story. This time the probing seemed more professional than before and was all over much quicker. "I can definitely feel something that needs to be investigated". Then, a question he almost seems a little embarrassed to ask "would I mind if the medical student had a feel?". "No, of course not", I replied... So she followed up – quite efficiently, for a beginner - while he explained his findings to both of us.

The outcome was that I would need to have an MRI scan and a biopsy to ascertain what was really happening. This would be at Lymington hospital. At this stage of the proceedings, I still wasn't too worried, remembering Dad's thirty year untouched enlarged prostate. I was handed a pack of Ciprofloxacin antibiotics with instructions to start the course the day before the biopsy appointment was due and suddenly it began to hit – this was real. It was explained that the biopsy would involve taking samples of material from the prostate, using needles steered under ultrasonic imaging. All accessed via my rear end but a mild local anaesthetic would be administered. As for the MRI, I'd had

one before and knew that was no big deal. I was given an information sheet about the biopsy procedure and it made the point about the need for the antibiotics and described all the potential after-effects. Certain things like blood in the urine was to be expected for two to four weeks after, and possible rectal bleeding. It also mentioned all the less-likely and rare things that could go wrong like infections, urinary blockages. It really would be better for the soul if they didn't say all that.

Now things were getting very real – perhaps it could be more serious after all. During a phone call to my sister shortly after the consultation, she picked up on a nervousness in my voice, but went on with comments along the lines, of “it's just old men's problems”. She is nurse manager of an old people's nursing home, and does see a lot of prostate problems. A letter duly arrived for an appointment on 19th September at Lymington Hospital at 09:00

Lymington Hospital

Lymington is some 35 miles from my house, and the appointment time, allowing for my usual huge timing margin meant I'd be leaving home at 0700; the very worst time to be on the M27 motorway into the New Forest. Then I made a very big mistake – I read the information leaflet that came with the ciprofloxacin. Advice to anyone, NEVER read medicine information sheets. It went on about all the possible side effects, and in particular possible dizziness and caution when driving. This warning, the thought of an early morning trip on the M27, all coupled with the fact I was going have needles poked up my rear end made me think perhaps driving there may not be a good idea; better look for some other transport option. I have no friends living near enough that I'd want to impose on for an early morning lift, so decided to take a taxi. It would be expensive, but what's money for. John and Sue, friends from the Bournemouth area, were happy to pick me up and drive me home afterwards. The day before the appointment I arranged with a local taxi company I hadn't used before to pick up at 0700 and take me there. That night I started the antibiotic course whose job, it had been explained, was to fight any infection from poking needles from a dirty area (the rectum) into clean internal organs.

The taxi arrived five minutes early the following morning – which immediately put them in my good books and guaranteed future custom. As Murphy's Law would have it, the motorway was amazingly clear, the taxi driver had never seen it so fast-flowing at that time in the morning. It turned out there had been an incident further back and very little was getting through. The result was that I arrived far-sooner than expected, with more than an hour to wait before the appointment. Lymington Hospital is a nice modern place on the northern edge of the town and it was no trouble killing an hour, getting my daily exercise fix walking around local roads.

After booking-in, the MRI scan was first. I got changed into a hospital gown and was led into the scanner room. It was clearly a much more advanced scanner than the one I'd experienced back in 1998. After being carefully positioned on my back on a very comfortable support bed they said the scan would take about 45 minutes and I'd need to stay very still. It was so comfortable that didn't look as if it would be a problem. I was rolled into the scanner assembly itself which is a tube surrounding me close in on all sides, and could well be claustrophobic to others. Knowing it contained superconducting magnets and liquid helium was all a bit awe-inspiring. They placed a pad on my chest (the RF source) and said it might feel a bit warm when operating. I immediately asked the operating frequency and power. Around 60MHz, they said, but it would automatically adapt and tune itself to me. And, 'a few watts'.

I'd been told it would make whirring and drumming and other noises and that that was 'quite normal'. In actual fact, the sounds it made were fascinating, very recognisable and reminiscent of a mixture of radio communication signals heard on a shortwave radio and the bass beat that we'd heard at Boomtown from distant performances late at night. It was all over in no time – I could have gone on listening to those noises for hours! However, a break of a couple of hours for lunch and a bit more walking around and sitting in the very nice grounds of the hospital, then it was time for the bit I wasn't looking forward to – the biopsy.

The Biopsy

Again after changing in a gown, being introduced to all the staff and moved onto a bed, the surgeon described the procedure they were going to do. I would receive a mild local anaesthetic in the rectum then they would insert the ultrasonic imaging probe. Using that as a guide, he would use an automatic jab-and-retract needle. Each time it took a sample I would hear a click. Then after a bit of time of him peering at the imager screen, it started. Each click coincided with a slight jolt that was a bit like a mild electric shock – they seemed a bit surprised I could feel it, but wasn't really too bad. The anticipation, every time the surgeon said something like "and now ..." was worse than the prod itself.

And that was it, time to go home. A visit to the loo, and sure enough bright red – but I had been expecting that. I didn't feel at all sore, in fact seemed perfectly OK. I could quite happily have driven myself back home, but John and Sue had been taking in the local scenery at Lymington and hanging on for my phone call. They turned up and we all returned back to my place, with me wondering 'now what'.

Not Encouraging News

A couple of days later I had a phone call from Southampton Hospital offering me an appointment in two days time with the uro-oncology consultant; it was followed up with a letter the next day. On the morning of 27th September I arrived in plenty of time for the 10:50 appointment and saw long queues building up at the main car park entrances. By a bit of quick thinking I managed to quickly dive into a pay-and-display slot as someone departed. Looks as if 10:00 is a bad time to arrive at the hospital; it turned out that was the start of visiting hours .

The consultant, Mr. Dyer called me into his office and I could tell by the look on his face it wasn't good news. You can sense that sort of thing immediately. He said the results of the scan and biopsy meant I had a prostate cancer that had spread just beyond the organ itself and into the seminal sacs. Stage T2/3 I recall, but can't remember the exact classification beyond that. Surgery wasn't a realistic option as access was so difficult but he was going to recommend a course of High Dose Rate radiotherapy. I was in a sort of shock at that point, assuming all sorts of things and outcomes, but he went on to explain that there were a couple of treatment options available. One was external beam radiotherapy which would take something like 28 days of visits over four weeks, but there was another option. Brachytherapy involved inserting radioactive sources directly into the affected areas. [1] I suddenly recalled I know someone who had mentioned having this done, radioactive seeds permanently implanted and he seemed to have been cured, so perked up a little bit at that point.

The consultant then handed me over to a specialist cancer nurse Alisa who, in conjunction with a colleague, it turned out were to be my appointed points of contact, my 'Key Workers', for all enquiries in the future. Alisa explained the brachytherapy process in more detail but also told me it would still involve a follow up of external beam appointments, although only half as many, five days a week for three weeks. She then went on to explain all the potential side effects that I could or might suffer, or not, or those that would be rare. It was a lot to take-in. The whole radiotherapy process would start in around three months time. Before that I would start on a course of hormone treatment whose task was to reduce testosterone levels, aiming to 'starve' the cancer, shrink it and stop it growing any further. This would be in the form of a three-monthly injection administered via my GP.

Not a lot really sank in at that point, I was still in mini-shock at hearing the diagnosis. But I was given several pamphlets to read, including ones on such seemingly unrelated subjects as 'pelvic floor exercises', as well as ones on radiotherapy and brachy [2]. All for me to read and take-in at leisure.

Now it was time to start breaking the news to people. First off, a phone call to my sister to tell her that my 'old man's problems' were rather more than that. My Bessie, Linda, who immediately said it was to be lunch at Rick-Stein's on her and gradually others who were all rather shocked to hear the news. One particularly valuable phone call was to Phil, an old friend from school and university days who was a GP. He told me just how good they were getting at prostate cancer treatment nowadays, and said he'd send me some information. Sure enough, shortly afterwards a scanned-in copy of the relevant pages from the GP's manual on managing prostate cancer appeared in my in-box. That discussed the relative merits of all the different treatments and more or less said the same as I'd been told, amplifying on most of the details and discussing their relative merits. Hormone treatment, brachytherapy and external radiation.

Appointments, Appointments

After that things happened fast and seemingly non-stop. First off was a phone call offering me an appointment for a bone scan on 29th September, then a letter for an appointment at a clinic on 4th October then one for a CT scan on 12th October – it all seemed non-stop.

The Full Density Bone scan was a particularly interesting session. The reason for this is to check that the cancer hasn't spread into the bones nearby and involves being injected with a radioactive isotope in a form that is taken up by the bone structure. The appointment was for 17:00, quite late in the afternoon, especially on a Friday, and the letter had warned in advance that the process would take several hours. The injection was composed of Technetium 99 which I was told had a radioactive half-life of just six hours. I was intrigued how something like that could be prepared and the radiographer explained it was made each morning and lasted throughout the day. I commented on how, this late in the evening, it would have lost over half its potency and was told the dose was adjusted appropriately. After the injection, I had to drink 750cc of water over two hours to aid its absorption. There was a small waiting room adjacent to the clinic with some comfortable armchairs. At that time of night it was all very quiet so I had little problem, relaxing feet up on a table and killing those two hours with a good book.

The scan itself was on a CT scanner in monitor mode looking for the pattern of X-rays being sent off from my bone structure. They clearly were checking the whole body as the scan lasted over half an hour. Towards the end they mentioned there was some anomaly in my head, on the right hand side of

the skull. I mentioned that years ago I'd had a minor head operation for an extradural haematoma after a car accident in 1984 and had had a burr hole drilled there. They seemed happy with that, but rescanned it anyway. Afterwards, walking through the empty hospital corridors and grounds in the late evening was surreal, reminding me of all the TV crime dramas where police pursue gunmen in the bowels of hospitals. The makers of those seem to have modelled their scenery on Level A of Southampton General!

Hormone Reduction

Dr Heath was going to be in charge of the radiotherapy and I was due at her clinic session a few days later. By this time I had studied all the documentation in some depth, and along with some Googling was more aware of everything that was going to happen. That day the appointment was for 14:00 and when I arrived every car park was absolutely jam packed full. Eventually I found a place in the car park of an auxiliary hospital across the road, in a really small space in a multi-storey few other drivers would dare attempt to get in - jam packed with barely room to open either door and squeeze past. It had taken twenty minutes to find that spot.

She explained the whole process again, confirming with me that I wanted the brachytherapy option as opposed to just external beam treatment. We arranged that when the external stuff was due, appointments would in general aim to be at around 10:00 to optimise my drive-in with the heavy traffic flow around Southampton suburbs and appalling car parking. I was given more leaflets and a letter for my GP detailing the drugs required for the hormone therapy. Interestingly, the GP was given a choice of three types and all had a price listed by them. Each appeared to cost in the region of £1000. The one the GP prescribed was *Prostap3* – apparently the most modern one on the list. The drug therapy was actually in two parts; the three-monthly injection had the main task, but that would cause an initial flare-up of testosterone, so I had a second course of tablets, starting five days before the injection whose task was to reduce this initial testosterone flare. I was also handed some prescriptions to pick up from the hospital pharmacy before the brachytherapy was due – but all that still seemed 'a long way off'. The clinic session ended with a blood sample taken for another PSA test, to 'establish a base line'

A full CT scan followed a few days after that, it was an early appointment which was fortunate as I had planned to travel to a convention that afternoon. The scan had to be preceded by a drink of iodine laden water; 600cc over the space of thirty minutes. The scan itself was pretty routine but they stated that for the next 48 hours or so I had to avoid stimulants like coffee and alcohol as my body needed to get rid of the iodine quickly and the irritants in these drinks would slow the process. So on the journey to the convention it was decaffeinated coffee at service stations - Starbucks' decaff turned out to be surprisingly good. At the convention I dutifully avoided the bar, for the first night anyway. A harbinger of things to come.

The first hormone injection followed a few days later, with the practice nurse seemingly a bit confused by the *Prostap3*. She carefully consulted the information sheet about its preparation and commented that she had never given that one before, it was quite unusual and needed careful mixing. But the process seemed to go flawlessly. I had been told that the reduction of testosterone could lead to side effects like joint pain and hot flushes, but for the first month or so there were very few. Some hot flushes at night but the side effects were pretty minimal apart from giving me a complete lack of interest in the shape of the female rear end.

It's all Gone Quiet.

The three months after that first injection were non-eventful. There were no more hospital appointments, hot flushes became slightly more frequent but rarely more than a slight annoyance when a few times I woke up at night sweating. It never lasted long. A few joint pains but all controlled by my regular exercise regime of at least four, and often more miles of walking each day. I even tried taking up running again but only went out three times. It was pleasing to see I could still run two to three miles without any problems - although I don't think I could ever get back to the half-marathon standard of 15 years earlier. Unfortunately poor weather and apathy put paid to any further attempts to get back to a regular running programme,.

Finally, in the first week of December, when I was almost beginning to think it possible the hospital had forgotten me, an appointment letter arrived for a pre-surgery clinic on 21st December – the solstice. This was followed by an appointment letter for the brachytherapy treatment to take place on 19th January 2018. Stage two was about to start.

The pre-surgery assessment seemed to be mostly concerned about my survival of the treatment to come. I was asked a host of questions about general health and had a quite comprehensive checkout – including the first EEG I'd ever experienced. Most of the assessment was concerned with whether I would survive anaesthetic but they also checked for the presence of MRSA, taking various swabs for analysis. They explained the procedure again and discussed transport and support when I was discharged. One overnight stay would be needed to ensure proper bladder operation and to make sure I was functioning normally before going home. After pointing out I lived alone, they said it really would be a good idea if I had someone with me for a few hours after I was let out; I said I'd try to arrange something. I seem to have passed all the tests with a clean bill-of-health but they did hand me a bottle of antibacterial wash with instructions to use it in the bath or shower the day of the procedure. MRSA and infection does seem a matter of very major concern.

At long last I picked up the pre-surgery medications from the hospital pharmacy – the prescriptions seemed to have been sitting on a shelf at home for ages. They consisted of the ciprofloxacin antibiotic I'd had before, to be started the night before as previously. Tamsulosin tablets, used to relax the urethra and bladder once treatment was underway had to be started five days before. The final item was an enema pack with instructions to administer it an hour or so beforehand. There's no way *that* was going to be a DIY job! But it appears the hospital are quite used to that situation and would do the task when I arrived on the day. I walked away from the pharmacy place thinking 'it all begins'.

Christmas and cold weather happened much as normal.

The Big Day

I had to be at the hospital at 0700 on the Friday of the event and had arranged a taxi from the same firm as before to collect me at 0530. Linda had somewhat reluctantly agreed to pick me up and take me home the next day in spite of having major concerns about parking her over-height land-rover in hospital car parks and finding her way round unfamiliar parts of the world, possibly in the dark. I know that feeling!

Needless to say I arrived ridiculously early, the reception was not even open, so once again it was the usual hang-around and read-a-book scenario. Eventually I was introduced to a nurse and shown to an individual side room. Into hospital gown and onto a bed where the enema was given – no need for any details there. About 30 minutes later various people started arriving to say hello, I rapidly lost track of who was who – not having a good memory for faces and people – but I can remember at least the surgeon, several specialist nurses, the anaesthetist and a radiographer. At some point I also recall being told my PSA level had dropped to 0.5 – the hormone therapy had done that. The surgeon explained the procedure in more detail and how the day would progress. He finished with the rather sobering comment that if my cancer had been spotted a year later, “... we’d be having a very different conversation now”.

I was to be taken to the operating theatre where the first stage would be a spinal anaesthetic to numb everything from the waist down. It was the first operating theatre I’d ever seen in reality and the similarity to those shown on TV dramas was striking – even down to the big timer clock on the wall. The anaesthetic was an injection into my lower back and I was asked to lean forward firmly, in the form of a strong jerk for it to be administered. I was then placed into position on my back, knees propped up and legs apart (the giving birth position someone, I forget who, joked). After a few minutes I could feel numbness gradually overcoming the lower regions and the anaesthetist kept testing different areas with a small prodding stick and cold-spray of ethyl chloride. It took something like 20 minutes to take hold completely and I recall her being surprised I could still wiggle my left toe some time after all other areas had succumbed. Eventually she was satisfied. A screen was rigged across at waist level so I couldn’t see anything – apparently people would go into shock seeing the operation underway, although the surgeon said it was there to hide his face from my view! Everyone seemed very light hearted and jocular. I was told a catheter was now being inserted – the screen hid the deed.

After some activity (which, of course, I couldn’t feel) he announced there was now a big ultrasound probe up my rear end, then he said he was starting to insert the needle tubes. I just lay back and listened and chatted as things happened around me, but it would have been interesting to see the image of my innards and what was going on. After a while he announced he was completed and there were fourteen needles poking into my prostate which had been locked in place with a block so they couldn’t now move. I would return to the side room and must try not to move too much to avoid disturbing the guide tubes. I was also told those fourteen needles protruded 10mm beyond the prostate and were all poking into my bladder. There would now be a wait of about three hours while several things happened. Primarily, they had to use the details from the earlier CT scan and the surgeon’s ultrasound guidance to plan the exact radiation planning. The timing and positioning of the radioactive seeds in each of the individual tubes had to be calculated and entered into the computer ready for the fully automated brachytherapy process.

I was given some food, a chicken sandwich and a tub of flavoured yoghurt which was the first food I'd had since the night before. I was told I had to drink 500 cc of water as my bladder had to be completely full for the treatment. It had to be kept full so the protruding needles could not damage the balloon keeping the catheter in place. It was explained that the catheter would be clamped off but if things got too painful they could drain off a maximum of 150cc, but no more. This wasn't going to be much fun, was it. So I lay there drinking and reading my book as the anaesthetic gradually wore off and I could gradually feel myself filling up. After about two hours I had to call the nurse in and say things were getting really painful. She duly bled-off a carefully measured 150cc and said they wouldn't be too much longer.

I was duly wheeled down to the radiotherapy room and introduced to the *Dalek*, a floor mounted bit of machinery that would insert the pellets. A number of small tubes protruded from the machine, these were attached to each of the fourteen needles currently sitting in my nether regions. At this point my bladder was getting quite uncomfortable but they refused to bleed off any more. The nurse explained that it had a capacity of well over a litre so wouldn't burst, and I was offered morphine to relieve the pain. This really was not FAIR! The morphine came in a small squeeze tube heavily laced with sweetener and as far as I could tell did absolutely nothing to help. It may have worked, but didn't feel as if it helped. When the tubes were all fixed and double-checked - the exact numbering and connection of each was vital - all the staff retired to a safe area and it began.

The machine gave a few clicks and whirrs and if I hadn't understood what was happening it would all have appeared to be a very big nothing. A radioactive pellet of iridium was being inserted in each tube in turn and the speed of insertion and retraction, and its dwell periods, were all automatically determined based on the data previously entered and based on the scans. After twenty minutes or so the radiographer came in and announced it was finished. The catheter tap was opened; relief at last! The collected urine in the bag was very red from the damage done by the 14 needles that had penetrated my bladder; it was now wounded. I would remain catheterised until any blood clots had cleared and it was starting to run clearer - ie any bleeding had stopped. I would now be taken to a ward for recovery.

I was taken to E-8, a male urology ward with six beds, the other five containing elderly men who seemed all in quite a bad way. My belongings arrived in good time and I settled down with my book, but actually found it more entertaining and interesting to people-watch. I was in no pain anywhere, in spite of being asked several times if I was. I kept myself busy with phone calls and more people-watching; nurses came with their regular observations and catheter bag emptying and measurements. As evening then night time arrived the outflow was still red and full of clots. At this stage I was still assuming the catheter would be removed the next day and I'd go home - but do remember thinking things could be a bit dodgy, making sure everything was under control. I was instructed to keep drinking and keep drinking water, it was essential to flush out the bladder properly to remove blood and clots. I hadn't been able to book a proper evening meal in the ward, so had to make do with more sandwiches and yoghurt; so my only intake for that day had been two sandwiches and two tubs - and a lot of fluid. Time passed surprisingly quickly, and I managed a decent night's sleep. At one point the chap in the bed opposite started throwing items out into the ward. Apparently his call button had failed and he needed a nurse urgently. I was just about to use my call-button on his behalf before help arrived.

Saturday morning activity started early in the ward with breakfast of cereal, toast and coffee - decent food at last. The morning passed with more people-watching, reading and the nurses coming to do

their 'obs'. Various doctors and nurses appeared, asking questions and checking, and around late morning they came to remove the catheter. That was not nice. I now had to drink lots of water and try to pee as much as possible and thoroughly flush myself out. The first 'natural' pee was excruciating. Very red, very painful and not too successful in spite of having a full bladder. This continued. I was being urged to keep drinking water but hesitated to do that if I couldn't relieve things. I still had visions of getting overfull and bursting. After several hours, by about mid afternoon I'd hassled the staff so much they decided that a doctor had better come and check. He suggested a flush out, to get rid of any blood clots inside that may be jamming the flow and put the catheter back in. That really was fun! Last time it had been inserted I'd been under anaesthetic; not this time. They did a back-wash where a large syringe was attached and water forced up the catheter into my bladder, then sucked out forcing blood clots and contents to be removed. All done several times. It was very painful.

An Extra Day

After a bit of discussion they decided that it would be best if I stayed in another night since normal operation clearly wasn't going to be resumed soon. So I ordered my dinner menu for later and settled back to people-watching, reading and telephoning. I managed to get a decent night's sleep. No throwing episodes this time. Next morning started as early and the same as before. After a while the medical team arrived to check me over and decided that the catheter collection bag could be removed once it was running clear. They would replace it with a tap that I would use to empty when I felt the need to do so. That would help train the bladder back into normal operations. Well, the idea sounded fine, it was a sort of 'outside tap' under my control. So back to waiting again. That might all sound tedious, but I found time passed very quickly; there was always something interesting going on.

Eventually the contents of the bag were running clearer, so I'd stopped bleeding inside and it was time to replace the collection bag with the tap. I was now on my own. I was told (once again) to keep drinking water. The trouble was that the damage done to my bladder meant that I felt the urge to pee often, almost continuously. So attempts to empty it were painful, frequently non-successful and any straining generated blood that came up around and outside the catheter tube. Furthermore, when my bladder really was full and I opened the tap to empty it, when flow was completed there was a sort of shockwave or kick back that gave a nasty painful jolt. Each time I had to empty it into a collection bottle and submit to one of the nurses for measurement of the quantity and inspection. Such fun. But it was always painful and I was beginning to despair that even this one extra day stay may not be sufficient. I was convinced blood clots were to blame and kept hassling the senior nurse on the ward who was quite a bit overworked with other patients in there; they all had more serious conditions than mine. He said another wash-out may help, although in retrospect that might have been more to satisfy me than was really needed. Mid-afternoon he arrived, along with a third year student nurse who I had seen on the ward all that day, she'd appeared so competent and efficient earlier that I hadn't realised she was even still a student. As before, the wash out was painful, perhaps even more so than the first time, although the student said I was one of the quietest people to bear this torture she had met. The flush out was clear – so they were right, there were no blood clots.

Self emptying gradually improved a little bit, but was still accompanied by shock-waves and occasionally blood around the outside at first, although that went away after a few sessions.

Eventually the medics came to the conclusion that I could go home complete with the catheter plus tap; a district nurse would come round to remove it the following Friday, five days away. I would be on my own from now on.

It was, by now, late afternoon on Sunday. I knew Linda would be very unhappy trying to negotiate getting here now, and the requirement for someone to be with me for a few hours after the anaesthetic had by now clearly gone away. So a taxi back was the obvious solution. To my surprise, the discharge nurse said the NHS would pay for the taxi. So, after gathering my various bits together, she escorted me down to the entrance lobby, ordered a taxi from their approved company and stayed with me until it arrived. I was rather surprised at the determination to do a handover to the driver and that I be never left on my own— it seems patients being discharged are not allowed to get out of the hospital environs without being in the presence of someone.

Back Home, with an Outside Tap

Now I was in my own surroundings, things generally felt better. The shockwave effect on emptying had abated and all I had to cope with now was keeping the tap in place while wearing normal clothes. A strap around my thigh held the pipework and it was almost possible to use the normal trouser fly to extract for emptying – although easier to just drop my trousers. The day following my return I called in at the GP's surgery to check up on the district nurse appointment, and was told they didn't deal with it there, but gave me a central telephone number to contact. Fully expecting the electronic obstacle course most central telephone services now run, it was delightful to have a real person answer within two rings. She confirmed that an appointment was indeed booked for Friday, and that it would be early in the morning to allow plenty of time to cope with any unforeseen problems. Later that day I got a call from a district nurse saying that if I wanted, there was a clinic place available for Thursday at a small local community hospital and I could have the catheter removed there, a day earlier than originally planned. After a bit of indecision I decided to stick with the original plan. One day was unimportant and I'd rather not have to be driving back, albeit only a couple of miles, with an unknown situation down below.

Life went on normally, the tap wasn't intrusive, or even visible when wearing normal trousers and going out walking, shopping etc. was no problem. I even managed a couple of decent semi-aerobic medium distance walks. My regular exercise regime is 'at least four miles every day' but the last few days in hospital had killed that cycle.

The idea of recovering from the effects of fourteen needles piercing my bladder gave a certain someone the idea that with all those holes it had gained properties akin to a teabag. So I now had to '*look after the teabag*'.

Friday morning arrived and not long after I got up from bed, sometime before 0900, just as I was wondering how long I'd have to spend thumb-twiddling, a car drove into the road with the driver clearly looking for a house number. The district nurse had arrived. After a few questions about my background and general state of health, she asked me the best place to go so I could lie down for the removal. A bit of playing with the syringe to empty the catheter's internal balloon, a yank, and it was gone – almost painless. Time to drink more water – what is it with water. The nurse said she'd ring later in the day to check I was Ok and functioning normally then went on her way. I asked if I could keep the catheter and she somewhat reluctantly (rules – rules –rules) said she'd 'leave me to dispose

of it in the domestic rubbish bin'. I still have it as a souvenir - all properly disinfected, of course. So that was it, how would I now function?

Actually, everything seemed very normal, no sign of blood in my urine, no pain, and not much problem getting started, except occasionally in the night. I was typically waking up twice or three times in the night, but never with any major urgency. There was certainly no leakage or lack of control, and certainly no bowel problems – all the scare stories in the leaflets were once again saying the worst, just like drug information leaflets. Better not to read them at all!

I was on Tamsulosin to keep things relaxed and emptying properly, but during that first week, after a couple of sessions during the night when I had urine retention for a few minutes, I noticed in one of the information leaflets it said Tamsulosin could be increased to two a day if needed. I initially tried that but was a bit concerned about doing it unsupervised, So I emailed Alissa, my Key-Worker for advice. I was a little surprised, a few hours after the email was sent, to get a phone call (from, I think, a radiologist or specialist nurse) who discussed the implications. They were on the lines, of 'it's safe to do so, but you're removing options for later increasing the dose to solve any problems brought on by the external radiation phase'. She was very familiar with that drug, and we spent some time going through its exact operation, and its timing and delay after ingestion. Alissa also emailed me back with a warning about potential dizzy spells, especially when standing up suddenly (which I had never mentioned having, but do suffer from). So I went back to the one-per-day regime and things slowly did improve. I was still getting up a few times in the middle of the night but by the time the next phase was to start, this was perhaps just twice, or even once, a night on average. Not vastly different to normal.

The Third Phase

A letter with an appointment for a CT scan on 29th January arrived soon after. This scan was planning for the next stage of beam radiotherapy. A letter followed soon after that with a list of fifteen radiotherapy appointments for Mondays to Fridays spread over a three week period starting mid-February. A clinic was scheduled for about half-way through. I was pleased to see that most of the appointments were for around 10:00 to 11:00, as agreed earlier with Dr Heath.

On arriving for the CT appointment it was the usual drink then wait for it to be absorbed – I was by now getting quite used to all the processes. The purpose of this scan was to map my innards accurately in preparation for the external beam treatment. So it was a case of finding an optimum position on the scanner bed where they tested various options of knee and head supports to allow me to stay absolutely still for extended periods while being as comfortable as possible. They then set up several laser pointers around me.

After the scan had completed, while still remaining in exactly the same place on the bed, they used the results and the position of the lasers to tattoo three small dots; one on each thigh and one on my abdomen. These were essentially the coordinates of my prostate and would be used for alignment when starting each of the daily sessions. They also informed me that I needed to be at each appointment at least half an hour before the scheduled time so I could hydrate properly, by having a half-litre drink of water when instructed, at a precise time before the actual treatment. What is it, really, about this insistence on drinking huge quantities of water?

Another blood sample for a PSA test and that was it for that visit. I went back home and resumed normal operations for the next two weeks. Side effects of the brachytherapy were barely noticeable, and what there were rapidly wore off after a few days. Just the occasional hesitancy before pee-flow started once in a while; and that was more often due to sitting down for extended periods, and a greater sensitivity to bladder contents. I had been advised to avoid caffeine and alcohol, so got quite used to decaffeinated coffee and no more than just a small gin every couple of days or so.

25 Sets of Traffic Lights and a Machine Fail

Eventually the day for the first radiotherapy appointment arrived, the 14th February was in the middle of the school half-term holidays. It was for 10:30 and even knowing the roads would be quite good due to lack of school traffic, I still allowed a huge margin on timing. Getting to the hospital well over an hour early, I once again went walking around the side roads and had breakfast (including a coffee) in one of the many restaurants there. I had by now found a small car park near the oncology department, round the back of the hospital, with a concealed area off in one corner that most visitors missed. So there was never a problem finding a parking space, and I could even take a slightly shorter route though back roads to reach it.

At this first session, the radiotherapist explained the procedure and how, in order to maintain accuracy, my innards had to be in near-enough the same condition each time. So on arriving I had to make sure bowels were empty, bladder first emptied then allowed to fill in a controlled way with the water which would properly hydrate me. Hence the 30 minute lead time. I was given a form with a barcode so that for each subsequent session I could scan myself in on a barcode reader on the wall of the department. The staff would be alerted to my arrival, inform me of any delay and would say when to start drinking. They really were sticking to that half a litre of water 30 minutes before regime.

It was explained that each session would start with the machine doing a CT scan to check the exact location of my innards, so the staff could make any adjustments they needed. They would be able to check the state of my innards just before exposing them to the X-ray beam – something that would lead to an amusing incident three days later. He then went on to say that some side effects would come on progressively over the period. The effect of the radiation would be cumulative and I would more than likely notice some effects on urination and bowel activity after a while. None of this was new information, I had seen it all mentioned in the pamphlets. I was also given a modified set of appointments times; annoyingly a few had been moved, several to earlier in the day and one, scheduled for two days' time, in the afternoon at 16:40.

So at that first session I duly drank my water when commanded and thirty minutes later was called to the machine – LINAC-F (Linear Accelerator). There was a small changing room adjacent to the LINAC bay where I could get changed into hospital gown, and a wheeled trolley for belongings. At the machine the same setup of knee and head supports that had been worked out at the planning scan were in place, the settings were all stored in my notes, so I clambered onto the bed and waited to see what would happen. But things didn't go to plan. The equipment was emitting a bleeping sound and it appeared this was a warning that one of the safety touch-guards was being triggered – they would have to call a technician to sort things out. Meanwhile, my bladder was getting uncomfortably full, so I was allowed to 'leak some off' while they sorted out the problem. That coffee first thing had been a very bad idea. It was also pointed out to me that coffee was not a good idea anyway as it has diuretic

properties that would upset the hydration programme with the water I had to drink beforehand. So no more early morning coffee.

The technician arrived and I got a look at the innards of the machine – circuitry that looked ancient to me and I knew would have been constructed about 15 – 20 years ago. Mentioning this to the technician, he said yes, spot-on, and after we'd had a brief chat, he said they had a vacancy in the department for a technician to look after the electronics – did I want a job; I'm not actually sure he was entirely joking.

After the warning mechanism was fixed we were ready to go. The bed was raised to working height, and the two radiologists, one on either side, spent several minutes moving me around slightly, lining up the three tattooed dots against a projected scale from laser pointers situated in the walls and ceiling shining onto the bed, showing markers and measurement digits. When I enquired what sort of accuracy they were aiming for, was told it was within a millimetre or so – pretty impressive for a huge flexible bulk like a human torso! When they were satisfied, the staff retired to their screened control room, assured me I was on a video link and that all I had to do was wave at the camera if I needed to alert them.

After a short delay the head-unit started moving round me doing its initial CT image scan. That only took a minute or two and then nothing more happened for two or three minutes. Suddenly there were a couple of clunks from somewhere under the bed and I felt it jar minutely. I found out later this was a minute adjustment of my position, done remotely based on their looking at the CT scan. Apparently, any more than three millimetres difference from the master scan and they need to correct the position – not bad accuracy.

The machine started buzzing – a warning of X-ray emissions - and again the head rotated around my nether regions, this time a bit more slowly. At one point it stopped briefly, then continued. After a complete circuit everything stopped, and the radiologists walked back into the room to say that was it for the day, I could go home. I asked why it stopped part way round, and they explained the X-ray beam is shaped by leaves in the head unit. The beam is altered in shape by these shutters as it moves round to match my treatment programme and the shape of the target. The delay was the shutter leaves rearranging their pattern – all completely automatic, all under computer control.

The next day my appointment was for the same time and as usual managed to get in a decent walk around the local scenery. Everything went exactly as it should, the appointment was on schedule with the barcode log-in, no breakdowns this time, the CT scan, a wait of a few minutes, a few clunks and the buzzing of the X-ray source, complete with its short delay part way round. I was away from the hospital not much more than an hour after logging in.

An Instruction to Fart

The third day, a Friday, was my oddly-timed appointment at 16:40. Everything went to plan until the CT scan had completed. There were no clunks and a longer delay than usual, then I heard voices approaching. Apparently, the CT scan showed a bubble of gas in my intestine, "... could I let it out. Perhaps you need to walk-around for a bit to help ...". I was being asked to fart to order! A short walk and all was satisfied. Back on to the bed, go through all the adjustments again and this time all went as it should. At the end of that session I was shown the CT image and the gas bubble was very obvious. I asked for a copy, or to be able to photograph the screen but they were very negative about

it. Strictly *Verboten*; images and photos are very definitely not for release unless the consultant agrees, so I decided to chase this up at a clinic session later.

The same procedure happened every weekday for the next two and a bit weeks, it was all becoming second nature. There was a Friends of the Hospital food outlet in the radiotherapy reception, well stocked with decent food like sandwiches, samosas and wraps, so that was breakfast each day. Pity I couldn't also partake of their coffee. Travel was worse now the school half-term holidays had finished. That first Monday took a very tedious 53 minutes to drive the 8.5 miles – just slow moving stop-start through the twenty-five sets of traffic lights between my house and the hospital. That was one of the worst days, things got slightly better as the weeks wore on. Fine changes to appointment times – perhaps only thirty minutes to an hour either way - made a huge difference to travel time. Occasionally appointments ran late, usually because of problems with the machines so I was told not to start drinking the water until a certain time. But most days everything went without a hitch.

About half-way through I had a short clinic session with one of the radiologists who explained what would happen when the programme was complete. She once again explained the after-effects I might experience and said that typically they would peak perhaps two weeks after the radiation course had completed. That timescale was new information. The effects of the radiation are cumulative, with a small amount of unavoidable damage being done to adjacent areas around the prostate, the bladder and rectum. *The teabag was definitely being nuked*. This would all take some time to repair itself. I was also told I would be on the hormone reducing treatment for 'probably another two years'.

Towards the end of the external beam radiotherapy programme, at the beginning of March, we had the abnormal weather, snow and high winds, the 'Beast from the East'. I was pretty confident all the roads I was using would have been cleared of snow as nearly all of them are main urban roads, some of which are emergency routes designated for ambulances. I rang the department asking for their status and saying I would be attempting to get in but could be very early. They said they'd try to fit me in as soon as I arrived. And that was the case; the schools had all been closed because of the weather and I got there in a record 27 minutes. Since many people from further afield had cancelled because of the snow, I managed to get my treatment an hour earlier than scheduled; the same thing happened the next day. Unfortunately, the day after that, another Monday, the schools were back and all the people who had missed work due to the snow were now on the road making up for lost time. It took over an hour to get in – that day was the worst ever for travel but the end was now in sight. The last two trips were marginally better, but I was certainly glad not to have to make that commute any more. There was one more "fart to order" command at my penultimate session – the quiet and extended delay after the CT scan, followed by approaching footsteps...

And on the 7th of March, that was it. All done, my prostate cancer treatment programme complete, and I was discharged with a letter for my GP where I had to pop in to get a repeat Tamsulosin prescription. A follow up appointment with the consultant, Dr. Heath was scheduled for 17th April, six weeks after the treatment was complete and side effects should be subsiding. I took away a form for a blood test to be arranged a week before that appointment.

Side effects and some Experimenting.

As predicted, after the radiotherapy was completed the side effects did worsen over the next two to three weeks. I was sometimes up three or four times in the night, occasionally having to walk around a bit to get things flowing, then a feeling of not emptying my bladder properly and having to complete the job five or ten minutes later. During the day things were a bit iffy too, especially if I allowed my bladder to become over-full. In that event it wouldn't then empty properly and two or three trips to the loo were needed over the next 20 – 30 minutes to complete the job. I walk a lot, and the cold weather around this time didn't help matters. Never anything too bad, but all a minor inconvenience especially when I needed to look for the nearest large tree or public loo. Things slowly improved; it was difficult to see any improvements as they happened but in retrospect changes for the better were observable. But it did seem ironic that after all that treatment, I now had the very problems that people with less serious prostate problems suffer. If I'd had those symptoms in the first place, everything would have been discovered much earlier.

Ever since recovering from the brachytherapy I had been on a dose of one Tamsulosin tablet per day. One side effect of that drug is that it lowers blood pressure, and if, as I do, you suffer from dizzy spells when standing it makes matters worse. There were one or two times while out walking, after bending down to say hello to a nice friendly dog, or retying my boot laces, or just rapidly climbing a steep hill, when I felt really dizzy on straightening up. After one rather alarming episode where I just managed to stay upright and avoid collapsing and rolling down the very wet and muddy St Catherine's Hill near Winchester, I thought it might be time to try to lower the Tamsulosin dose. Initially I dropped to one every 36 hours – no real change to the still-present side effects. Then extended to alternate days taking it in the evening, then I tried a 2.5 day gap. It seemed OK, I was still getting up perhaps three times in the night but I'd been doing that at one-per-day earlier on anyway. So I tried a three day cycle, the first one actually being a 3.5 day gap to get back to evening timings. The first couple of times after I moved to the three-day cycle there were a few problems during the second night with getting going – but nothing a few moments walking around looking at the stars (well, actually it was all rain and clouds over that period) didn't cure.

And that's where we are now. I'm writing this paragraph after having been on one-tablet every three days for nearly two weeks. Day time pee-flow issues are no problem at all, although flow rate is reduced on day three if I've been sitting around inactive for an extensive period. Night time I may be up twice, or is it three times or four? It has become so habitual I can't actually remember and never have a problem subsequently falling asleep again – hence a bit of uncertainty over just how many times I do get up. I'm sure one night recently it was just the once, but that may have been caused by a bit of dehydration that day.

Now we are Now! Into Diary Mode

I started writing this missive during the waiting times for radiotherapy each day - the compulsory drink of water and 30 minute wait - while I could still remember earlier events in some detail. Being in the hospital environment while writing meant it was easy to recall and things had remained mostly fresh in the memory. But we're now up to date – it's 14th April 2018 as I write this. Dr. Heath's Clinic is still three days in the future; I had a blood sample taken for the PSA test two days ago; the next *Prostap3* injection is scheduled for Monday; the day after that, the clinic session.

So everything that now follows can be written as a diary, which is just as well as precise details of what happened over the last six months are beginning to fade now. This is the second day of the three-day Tamsulosin cycle, so tonight has the potential for being the worst and I take the next one tomorrow evening. Or, if things are perfectly OK (no retention) I may try another 3.5 day attempt with the intention of extending to one every four days. I emailed my keyworkers for advice on this, but the response was a bit ambiguous – seems it really is my decision.

Treatment Diary Notes

16 April – I had my *Prostap3* top-up injection. Again, the nurse doing it expressed surprise that I was having this drug, stating it was the expensive one and had to be made up each time. That involves a few minutes gently tipping the syringe to mix the constituents before injecting abdominally. Tamsulosin dose remaining at one every three days – I've chickened out of trying for a four-day cycle.

17 April – Clinic appointment with the consultant, Dr. Heath at 09:00. [37 minute journey time today – but it seemed longer]. All appears to be satisfactory. PSA level is down at 0.2 which is as expected and 'good'. The hormone treatment will need to continue while monitoring the PSA level, but if I choose to I could now go onto a daily tablet regime. Think I prefer to stay with three-monthly injections.

Apparently I'm doing the right thing with Tamsulosin dosage – just vary it until things feel right. She said that this is still in the early stages after radiotherapy, so after-effects are still to be expected. It certainly doesn't seem like it's still 'early stages'!

I'm trying to get a copy of the CT scan of that third radiotherapy appointment where the gas bubble was showing and the hilarious instruction issued, so asked about getting a copy. In spite of our right under Data Protection laws to see our medical notes, it is proving almost impossible to get a copy of that. I was passed from secretary to secretary before finally admitting defeat and leaving a phone message with Dr Heath's secretary. I intend to keep going and get a copy of that CT image. So far today there has been no reply to that message.

19th April – Still haven't taken a Tamsulosin tablet which makes it a four-day gap. Things are definitely improving there. I was up three times last night, and once needed five minutes of waiting around star gazing (clear skies this time, warm enough to sit outside) before being able to empty properly; But tonight will be the decider, any problems and will take another one tomorrow giving a 4.5 or 5 day gap.

Still no reply to the phone message re. the CT scan image

21st April – Managed to hold off on the Tamsulosin until this evening. Six days and mostly functioning as normal, but today was becoming a bit constricted and the old symptoms were back, so I didn't want to trust another night. A significantly longer period without taking it than I was expecting – progress. I appear to have gained weight, was always 70 to 70.5kg for several years but now more like a consistent 71 to 71.5kg

22nd April – Some noticeable muscle and joint aches in the morning. It looks like the *Prostap3* top-up has hit. They had more-or-less gone by afternoon and not noticeable as I write this. Or a totally unrelated cause – who knows. Very definitely more flabby – let's blame the hormone treatment, although I'm sure I am eating more these days.

23rd April – This morning I went out for a run. 4 miles, of which the last 1.5 were more walk-run-walk-run. Around 48 minutes, but didn't time it accurately. Leg muscles will probably regret it later

30th April - Leg muscles took several days to recover from that run, I definitely overdid it doing 4 miles at faster than a gentle jog. Appointment letter arrived for "Prostate Cancer Supported Self-Management Workshop arrived for 8th June. Basically, I have regular PSA tests, results are fed into the system and only contact with hospital is if the values increase, or if I have any other issues to raise.

1nd May – Still got slight joint aches, but walks, some longer than usual, eg. 11km yesterday, and regular exercise reduces them. Forcing myself to cut down on nibbles, especially in the evening and experimenting with slight changes to eating plan – determined to get this extra weight gain down. Tamsulosin averaging one every 5 - 6 days. Bit uncomfortable towards the end of that period each time. Still getting up several times in the night; I think lying on the offending organ has as much as anything to do with that – ought to try sleeping on my back more often. Finally... got a call from the hospital giving me a department, contact name and phone number for getting the image of that CT scan. Took their time getting back to me, but at least they did. Must follow it up ...

12th May – No real changes. Another short run a few days ago. Perhaps lost 0.5 to 0.8kg so the extra exercise and stopping nibbling has helped. Feel some flabbiness up top – moobs developing due to testosterone suppression? Specially noticeable when I'm running. Now going for a longer gap without Tamsulosin, 8 days now and the effects are noticeable, but nothing unpleasant. Waking up less at night now.

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