

Brian Lewis's experiences of HIFU

I was interested to read of this method of treating prostate cancer in the Summer 2020 issue of our newsletter. It may be of interest to members if I relate how I stumbled across this method of treatment and how it affected me after I had it.

In early Spring 2008, following discomfort when my 'tackle' was performing its evacuation function, I went to my GP. She very quickly came to the conclusion that I had prostate cancer and carried out a PSA test, This confirmed her assessment, so she referred me to Southmead Hospital. Whilst I was waiting I sought information and was astonished by the varying methods of treatment. The alternatives seemed so diverse, so I dug deeper, seeking information from a number of sources such as Johns Hopkins Hospital in Baltimore and UCH London. (In fact my family joked that I became so knowledgeable that given a large enough mirror, I could have probably carried out the operation myself)!

Shortly after, I received an appointment to attend Southmead. The first test was firing what looked like a starting pistol, twelve times up my rectum. (So undignified...). The next appointment found me in front of a consultant. Without any vestige of a bedside manner, he told me I should come in and have my prostate gland removed. Now I had heard that this most often results in incontinence, so my reply was that it seemed there was at least a dozen alternative treatments to removal and nobody was going to lay a scalpel on me until we have gone through each type of treatment, with an explanation of why each was not suitable for me. The consultant lost patience, mumbling, 'I haven't got time for all that', but he did offer to email me his thoughts. I received nothing.

So it was back to the drawing board. I looked on the register of Bristol area Consultants and made a list of those who dealt with Urology. Early on the list was Mr Amit Bahl. So I rang his secretary and asked if i could 'buy' an hour of his time. We met and I was impressed by his professionalism. Personally he worked with the 'nuclear option'. Now I have always been opposed to any form of nuclear power generation, so I guess I allowed this view to influence my judgement. In my searches, I had come across HIFU, (High Intensity Focused Ultrasound), and discussed this with Mr Bahl. He then referred me to a practitioner - Raj Persad. We met and from talking to him (another real professional), I concluded that HIFU was the way forward. It was then not available on the NHS and the cost was staggering, but fortunately, my wife and I subscribed to private health insurance with WPA. So I approached them and they, wonderful people that they are, agreed to fund the costs.

The treatment date was set as being 9 May 2008. I was told to be at St. Mary's (Nuffield) hospital at half past twelve in the afternoon. I worked at my desk until noon and my wife drove me there. Treatment started with the inevitable chemical enema, then the pre-med injection and I remembered nothing until I woke up about midnight. They told me the operation took six hours. I was in no pain and slept soundly. The next morning Mr Persad visited me and was evidently pleased with my progress, as I was told I could go home. My wife drove me back and I went straight to my desk and continued working. What follows are notes I made at the time.

The surprise is that I did not experiencing pain or discomfort from my rearmost regions. I fully expected to spend most of the day lying on my stomach - in fact the family were making jokes about learning to surfboard. On day 3 I jumped up onto the (unsprung) tractor and cut some grass without any problems at all. Also, my stools were unbloodied. Clearly HIFU is non invasive to a remarkable degree.

Never in my life have I suffered reactions from surgical plaster. Heaven only knows what

Nuffield Hospitals use, but I developed not only surface sores, but ugly purple weals under the skin where capillaries had burst. The catheter has been held by 100mm x 80mm 'H' shaped plasters and the skin under these was especially bad. These had a tenacious grip on my skin and getting them off was a nightmare, but fortunately in my business I use Iso Propyl Alcohol, both in 25 litre drums and - more usefully, in aerosol cans. IPA is the spirit you smell in the hand washing gel as used in hospitals and I had placed a quantity in a bathroom to be used as a cleaner and disinfectant. I found that it softened the adhesive on the plaster, making removal easier.

I used micropore to re affixed the catheter, but being made from silicone, it was not secured very well and pulled when I walked. Fortunately, at this time, my GP 'phoned to see how I was getting on and on hearing my comments, she sent the District Nurse to see what could be done. She promptly replaced the micropore by a purpose designed catheter/tubing retain strap manufactured by Manfred Sauer - Tel: 0870 1 904 100 (usual disclaimer). This was brilliant - Velcro elastic leg strap with additional covering tab and two self-adhesive micro hook tabs. These fit face to face over the catheter, are secured to the Velcro leg strap and then covered with the additional Velcro covering. Simple, fool proof, has never failed and you do not know you are wearing it. Why it is not standard issue in all hospitals is beyond me. The District Nurse also provided me with a 500ml day bag. The strapped onto my leg just below the knee. After a few minutes I forgot I was wearing it, even when it was almost full. I only used this when I went out - my thinking was that an unrestricted exit flow was not helping regain muscle control.

The tube from the catheter to the collection bag has to have an unobstructed path - no problem when you are in hospital wearing a surgical gown, but requiring a different approach when wearing pyjamas.

I found that a vertical slit about 8 inches long, cut in them just above the knee provided a solution. My catheter has a flip-flop shut off valve on the end of it which tended to catch on the slit. The solution was to remove this at night and plug the bag directly into the catheter.

Now I just could not get along with wearing paper incontinence pants, as sold by Boots and others during the day - although I seem to have no problems using them when in bed, presumably because I am lying still, rather than walking. I felt I had a brick between my legs. The amount of absorbent material is clearly designed to cope with the effects of incontinence, whereas I needed something just sufficient to deal with the 2-3 ml of blood that was oozing from my penis each hour. Pads designed specifically for Men have the same problem. I tried all variations, (I have enough types of pads/pants/towels here to open a museum), but wasn't happy with any of them. As always, Mrs. L had an answer and clearly, togetherness is standing by the sanitary towel gondola in Superdrug, discussing the merits of sizes, absorbencies, wings or no wings, etc. (It certainly gives a new twist to 'sisterhood'....). Always Ultra Panty Liners are the perfect solution. (Now I begin to appreciate what ladies have to put up with for 40+ years of their lives....).

My testicles were very tender and the ball sac had swollen tremendously. (Country folk will know what I mean when I say that in size I went from Dexter to Limousin). They need support, so if you normally wear Boxer Shorts, Y Fronts or similar, I suggest you pack them away and purchase the no-fly pouch type. These are much more comfortable and I probably will stay with them. Incidentally, it was when Mrs. L was checking my ball sac that I found,

to my immense relief, that my erectile function did not seem in any way impaired.....

For some while before the operation, my bladder fullness had been getting me up 2-3 times in the night and I was surprised to find that this routine continued. However, after few days I slept on through the night undisturbed, save for one night when my two-litre night bag was full to bursting and would admit no more urine. All this time my urine was clear.

On day 13 things began to change. The swelling in my ball sac began to go down and I was standing at the WC and my penis began to flow. Probably no more than 30-40 ml. The first drops were bloody but then it ran clear. This repeated itself spasmodically throughout that day - sometime via both exits, other times only via the catheter. This was the first time I went out not wearing the day bag and I experienced no problems. The next morning the contents of my night bag were bright red with a small solids content. It has taken its time, but the scabbing on my prostate wound is separating.

On day 14 I managed about a one third/two third split between penis and catheter. The muscles seem to be in good shape - I can stop the flow at will. The oozing of blood from my penis has now stopped between evacuations.

It is day 15 and I have just weighed myself. I cannot believe I am 10lb heavier than before the operation. Clearly I am not moving about as much as I usually do, but even so! There is a requirement to flush myself out with extra fluids and in truth, I do not like the taste of water - from any source. So I have been putting away 2 - 1 litre cartons of Waitrose's best Grape and/or Apple Juice each day. At 450 calories per litre, no wonder I have gained weight! The penis/catheter exit split is now about 40/60 but my urine contains sizeable clots, is red and very cloudy. I have stopped wearing Panty Liners (sorry Proctor & Gamble - I hope your profits don't take a dip....). The flip-flop valve on the catheter is leaking. Fortunately the District Nurse suggested it might and gave me a spare. District Nurses know everything!

The Urology Nurse telephoned and I am having the catheter removed on Friday 30 May. That is 22 days after having the thing inserted. Will I miss it? I think not!

Day 16. Still clotting quite heavily. Mrs. L has said I can drive today, so I am off to a village about 10 miles away. I forgot to mention earlier that, before the operation I found that John Lewis has a goodly variety of waterproof fitted sheets. The one I chose appears to be a micro porous material faced with a flannelette flock. Forget the hospital type rubber sheets which radiate heat back at you and are noisy, you just do not know this one is fitted (usual disclaimer). I am conscious of the fact that I must get my muscles back in order - this unrestricted peeing into a bag at night must have relaxed them greatly. So tomorrow I am going to sleep without the night bag and see what happens.

Day 17. I must get my muscles back in order - this unrestricted peeing into a bag at night must have relaxed them greatly. So tonight I am going to sleep without the night bag and see what happens.

Day 18. A dry bed, but I did have to get up 4 times in the night. The urine coming from my penis is still bloody and very cloudy, whilst that from the catheter is quite clear. Every time I urinate now, I do so in a measuring cylinder and am keeping a log of 'how much comes from where'. The aim is to have all but about 100ml exiting via the penis. Sadly I am a long way

from that objective.

Day 22. I am due to have the catheter removed later today. However, very little is coming out of my penis. At least the colour has changed. It is now a darker red, suggesting that the bleeding has stopped and what is coming out now is old blood. Quite 'sludgy' - reminds me of the sediment in the bottom of a bottle of good vintage port....

Day 23. I still have the catheter. It does not bother me - I hardly know you have it. We have made an appointment to reassess the situation on Day 28. My 'night-time excursions' are down to one or two trips. Records show that my bladder will hold about 450mls, then 'digs me in the ribs' and insists I get up. One really good thing, I have never wet myself, or leaked in any way, suggesting that my concerns that I would end up incontinent are unfounded. One of the benefits of HIFU perhaps?

Day 28. Although my urine is moving back towards its usual pale straw colour, I still cannot pee in quantity from my penis. The Urology Nurse tells me, with a smile, that she once had a patient who had his catheter for 2 months.... She gets the Consultant who performed the operation to reassure me that all is well. His comment was that I had a 'prizewinning prostate which is, even at this stage, very swollen and thus preventing the free passage of urine. So I leave with the catheter. We now make an appointment for 17 June, (Just as well they decided to leave it for almost two weeks. Mrs. L goes up to Queens next week - I am a 'tennis widower'). We will see what happens then. The nurse advises that she will 'phone me next week and if the situation improves I can pop in and she will do her stuff.

In all I have written in the 'blog' there are two important - and probably quite obvious matters I have not mentioned. The first is my ability to have an orgasm. The answer is 'yes' and the sensations are the same. The other is whether the operation has been a success. I am told it is too early to make a reliable test, so I will have to wait and see.

This is an update on my post HIFU experiences since my last 'blog' on 6 June. You may recall that I went to the Urology nurse on day 28 and it was decided that I still had not healed sufficiently and the catheter remained.

Day 32. I have been measuring the twin outputs every time I urinate. The residual flow from the catheter is never less than 75ml nor more than 175ml. However, it is now moving towards the lower amount each time. So I decide to try an experiment. I stop evacuating via the catheter except for the last pee of the day. Surprisingly, it is still within the same range. Better still, not using this during the day has not increased the number of 'nightly excursions'.

Blood loss seems to be concentrated in the first pee of the day and is just a few drops. The urine is cloudy and contains white debris. I continue this practice each day and am pleased to find the residual amount is getting smaller each day.

Day 36. The Urology nurse 'phones and asks how I am getting on. I give her the data and she suggests I come and see her early next week.

Day 40. I am in the Urology nurse's rooms, peering into a funnel. When I have expelled all I can, the catheter is opened and the outflow measured. The nurse seems happy and gets me to lie on an examination table with my midriff exposed. Now this lady has cunning and whilst

chatting about nothing in particular, she deflates the balloon holding the catheter in my bladder. Without a word she gives a sharp tug and it is out. No pain really, more a sharp prick.

She waves it in the air. "Would you like to keep it as a memento?" she asks. As politely as I can, for she really is a delightful lady, I give her firm instructions as to its disposal.... She dresses the exit wound. Now I spent most of my working life in the construction plant industry, where cuts, abrasions and even broken bones have been regular companions. I have learnt that wounds heal fastest when the air can get at them. So before retiring for the night remove all bandages. Next morning my pyjamas are unmarked and the wound looks good. So I do not replace the bandage and have had no problems since.

Day 43. The nurse 'phones. We make an appointment for a PSA test on 7 August. Here my notes stopped.

It is now 12 years since I had this operation. There has been no hint of a recurrence. Knowing what I know now, would I have the same operation again? Absolutely.

Brian Lewis