

My decision to have HIFU treatment, by David Griffiths

## DIAGNOSIS

I was diagnosed with prostate cancer in November 2018. Three years earlier I had been for a routine PSA check after reading about the importance for men of my age to be tested. The results were low around 5.4 and it was recommended I have regular tests every six months to monitor PSA levels. I didn't because of another more serious health condition. For five years I suffered regular agonisingly painful stomach pain until, after being rushed to A&E, a blood test revealed I had pancreatitis. When I finally remembered two years later I should have been having PSA tests I went back to my GP. The results this time revealed a PSA level of 7.1 and an appointment with Urology was arranged at Southmead Hospital. My consultant thought there was a strong likelihood that cancer was present and advised a biopsy. I wasn't keen so he arranged for an MRI scan. The scan revealed a shadow and at the next appointment the consultant urged me to have a biopsy. The result confirmed intermediate grade prostate cancer with 3 cores right 5% seven cores left 15% a Gleason score of 3+4.

## TREATMENT OPTIONS

My cancer nurse outlined my options for treatment at Southmead Hospital, which were: a radical prostatectomy, external beam radiotherapy or brachytherapy monotherapy. I was given comprehensive literature for each treatment which the nurse discussed with me in detail. She felt I should make a decision sooner rather than later and also gave

me details of the prostate cancer support group and the national prostate cancer helpline.

I was quite calm upon hearing the diagnosis. My stomach pains had not yet been diagnosed so having prostate cancer that was causing me no symptoms was nothing compared to the pain I was experiencing on a regular basis. I was trying a dietary programme which the surgeon agreed I should finish before making a decision about surgery. He said 3 months would be quite safe to wait and indicated that I could delay a decision for up to a year but no longer. I had just turned 70 if I delayed any longer I would be too old to be considered for surgery. I liked the surgeon he was very positive and said surgery for me should be very straightforward and because I was fit and healthy I should make a good recovery.

I went away and read all the literature plus researching online. I talked and listened to people at the Macmillan drop-in sessions, the prostate cancer support group and discussing them with my wife. What I learned was that every one is different. Everyone had a different story. Some recovered well from surgery while others had problems, some quite serious and life changing. Some made good progress to start with but then had urinary and bowel problems later. I talked to one man, a surgeon, who was very bitter about his treatment and urged me to think hard before having surgery.

It seemed to me that ideas and research into prostate cancer were changing all the time. I read a lot of reports criticising early intervention through surgery when the

research showed that many would survive at my age without surgical intervention. In my support group I was surprised to find that nearly everyone had opted for surgery and I could find no one who had chosen radiotherapy or brachytherapy. There were quite a few who were having to have radiotherapy following surgery where their cancer had spread to the bowel and other parts or their cancer had been diagnosed too late for them to have surgery.

I first decided I would go for brachytherapy based on lower percentages of possible side effects urinary, erectile and bowel problems. However I also began to see this as not only a treatment choice but a quality of life choice. Given my age, should I have surgery or radiotherapy causing me to have resulting problems for the rest of my life or should I take a chance that I would die before the cancer became a problem, and enjoy the life I have left free of the associate problems of treatment? Its a lonely and scary place to be. Only I could make the decision. The consultants were urging me to have treatment and I didn't fancy the possible consequences.

I then read a very positive article in Prostate Matters by Timon Colegrove, who had been to Germany for a new treatment called Proton Beam Therapy, which had less risk of the usual related health issues of current available treatments on the NHS. I contacted the team in Germany to find out more and what the costs would be. I liked what I read about this treatment. I could just about afford it and, though I would not normally consider private treatment, I decided my future health was worth

the outlay.

At the same time I got to wondering if there were any other new treatments I might have missed. I phoned the national prostate helpline. I wanted to discuss my options again before making a final decision. The nurse mentioned a trial at Charing Cross hospital for a new treatment called High Intensity Focused Ultrasound or HIFU for short. I went to their website, read about the treatment and found it was similar to the Proton Beam Therapy. I emailed Professor Ahmed, the consultant in charge, with my details, MRI and biopsy results. With a referral from my GP he said he would consider me for the trial. Hooray!

#### HIFU PROCEDURE

HIFU involves firing High Intensity Ultrasound beams guided by ultrasound imaging from the probe, to heat and destroy the cancer cells. This means that only the cancerous parts of the prostate are destroyed, leaving healthy areas intact. There is less risk of damage to surrounding nerves and damage to the bowel is very rare. The problem with new treatments is that there are fewer case studies and statistics available compared with long-term treatments. HIFU has been around for just over ten years so nothing is known about the long-term effects of treatment beyond that period. However the statistics they do have are very favourable compared with surgery or radiotherapy. Although the side effects are the same as other treatments, the percentages are smaller. So I opted for HIFU treatment.

Even though I had already had a biopsy and MRI in

Bristol the Charing Cross team wanted me to have another because this was important for the detail they needed for accurate targeting of the HIFU beams. I travelled to London to have these. I was asked if I would allow some extra samples to be taken in the biopsy for a research project into prostate cancer, to which I willingly agreed. For the biopsy I had in Bristol I was given a general anaesthetic and was relatively pain free but in London I was given only a local anaesthetic and the biopsy was painful.

### A SLIGHT PROBLEM

The biopsy revealed that the cancer was mainly on the left side but had grown more on the right side since my first biopsy. The consultant explained that with HIFU they normally treated only one side of the prostate. The growth on the other side meant I could not be included in their trial research but they were happy to go ahead and treat me. . of the prostate.

Then Covid-19 hit the UK. My first date for the HIFU was postponed because I had cold symptoms. The second date was scheduled for May 2020 in the middle of lockdown. I was fortunate to have friends who were prepared to let my wife and I stay over with them. They also offered to drive me to the hospital and pick me up so I wouldn't have to use public transport. I had to arrive two days before the operation to have a Covid test which was negative. My operation was at a private hospital commandeered by the NHS to keep away from the NHS hospitals with A&E departments to reduce the risk of infection to non-Covid patients.

## THE OP

It was a day procedure. Being driven to the hospital through empty London streets was eerie. The hospital itself was very quiet with none of the usual bustle. I was shown to my room where I had to shower and scrub with anti bacterial soap. I was then given an enema to empty my bowels. I then met the surgeon who explained the procedure and what to expect afterwards. I was shown how to use a catheter, how to change the bag and how to change all the components. I would be expected to use the bag at night and a tap flow during the day. She gave me her card to call her if I had any questions after the operation.

As I was prepared for surgery I wondered if I had made the right choice. The consultant Professor Ahmed was present to oversee the procedure for all his patients, which was reassuring.

## POST OP

As consciousness returned after the op I was disoriented. I was aware of intense pain in my penis and bladder like I really needed to urinate and as I realised where I was I thought "What have I done?" The recovery team all in PPE seemed puzzled at the amount of pain I had. They gave me morphine to ease the pain. It was very uncomfortable and not what I had expected. It took a good hour for the pain to begin to recede before I was able to go to recovery. The surgeon told me the op had been very successful. She had also been more radical and treated some but not all of the right side. The advantage being the cancer remaining was small and I may not need further treatment but would need to be

monitored.

I stayed over night with our friends and the next day my wife drove me home. I had bought an air cushion to sit on in case of discomfort but apart from the pain on waking after the op I was now pain free.

### TRIAL WITHOUT CATHETER

I had to arrange with my local community nurse team for trial without catheter after 10 days. Although this had been mentioned I had not understood the process. After 10 days the community nurse would remove the catheter and see if I could empty my bladder with a normal flow of urine. The first trial I had a good flow to start with but after the nurse left I had problems and had to call to get a new catheter fitted. They responded immediately. My consultant suggested keeping the catheter for another week. The second trial without catheter was successful.

### FOLLOW UP

After 2 months I had a PSA test. My PSA was down to 2.7. My consultant was very pleased. She also expected the PSA to rise. Another test 3 month later was 2.9. Again the consultant was pleased. I had no other symptoms I was feeling healthy and no other side effects apart from one.

### ERECTILE FUNCTION

While I still had the catheter I noticed that I was occasionally having early morning erections. That felt really strange and because of the catheter the erection was really hard. Still I thought that was a good sign as this was an issue I was particularly concerned about in

choosing treatments. HIFU stats showed only a 30% possibility of erectile dysfunction. So after the removal of the catheter and feeling well again I was disappointed to find I could only get a partial erection. My consultant said this should be only temporary and it could take a year for the prostate to fully recover from the HIFU treatment. She asked my doctor to prescribe Tadalafil, which Professor Ahmed prefers to Viagra. I am pleased to say this has helped on a very small dose. Having to plan ahead to take the tablet does take the spontaneity out of love-making.

## CONCLUSION

So far I think I made the right decision. Hardly any side effects and good prognosis with the proviso the small amount of cancer on the right side may grow and at some time in the future that may need treating with HIFU. One advantage of HIFU is that treatment can be repeated. It also means I will not have a zero PSA count.

I will continue to be monitored by Charing Cross Urology. The medical team are great as were my local community nurse team. I am so grateful to the NHS and will fight all the way to save it from privateers.

What I will never know of course is what would have happened if I had decided to do nothing. The indications were the cancer was growing and it was moderately aggressive. Would I have outlived it before it became life threatening? Who knows?



