

John's journey with Prostate Cancer

My name is John and two months after my 64th birthday I became “the one”, the one in eight statistic of men who would develop prostate cancer. This diagnosis has sent me on a journey which I feel is important to share as research has indicated that it is a totally curable condition if diagnosed in the early stages. Many men seem to follow the Ostrich syndrome or treat it as the Elephant in the room. It won't happen to them, it is always someone else.

The Beginning

Like other men before me, I had the symptoms long before I self referred to my GP, night time multiple visits to the toilet, straining, stopping mid flow. However I finally decided to see my doctor on the 11th August 2017 a Thursday. The doctor I saw that day was a Locum at the time (I am pleased to say he is now a full member of the Practice), he listened to me describe the symptoms and took a Urine and Blood Sample, then advised me that the results would be available in a few days. He also told me something I already knew, that I had the classic symptoms of Prostate trouble.

On the Monday morning about 11.45 I received a telephone call from the Surgery informing me that my Blood Test results had been received and that one of the Doctors' wished to discuss them with me, and it just so happened that an appointment was available for me in 15 minutes time. I realised at that time that the outcome was not going to be good. Something flags up in your brain that the Surgery and Doctor are creating space for you, so it is either serious or urgent maybe even both.

The Tests

Off I went to the Surgery and met the Doctor who advised that the Blood Test revealed a high PSA reading which although it is an indicator of Prostate Cancer, it is not conclusive. The next stage being a physical examination via the back passage, assuring me that although perhaps embarrassing would not be painful. After the said examination the Doctor told me that the Prostate was an irregular shape and enlarged, and that I would need a biopsy to further diagnose what was going on.

I have a daughter who lives in Wales and every year my wife travels over to look after three of our grandchildren for three weeks during school holidays, whilst I stay at home and only travel over for the last week. My GP advised that the Biopsy appointment would be within two weeks and as I was travelling to Wales on the following day, it would be OK for me to go.

Sharing the news

Traveling to Wales the next morning was a really unnerving experience, my thoughts were “how am I going to tell my wife that I may have cancer”. I did not want my daughter or grandchildren to know anything was wrong at that stage and was concerned that I would not get the right opportunity to tell my wife.

When I arrived at my daughter’s house my concerns were ill founded, my daughter was still at work and my son-in-law had taken the grandchildren to the park leaving my wife alone in the house. I explained the visit to the Doctor and subsequent tests and examination and that I was waiting for a Hospital Appointment for the biopsy. Being the considerate and loving person that she is, her reply was “we will get through this together”. We both

agreed that we would not tell our children, or anyone else for that matter, until we had conclusive answers. Telling someone you are undergoing tests usually opens up a plethora of questions of what happens next, or what about this or that.

The Biopsy

Later that day Altnagelvin Hospital rang and gave me a date for my biopsy, 23rd August, the day after I was due to return from Wales. Of course I was eager to get the process over with as soon as possible, then I would know one way or another.

On 22nd August I left Wales as planned traveling by Boat via Dublin, of course I hadn't paid much attention to the weather forecast so much to my surprise when the vessel docked there was a thunderstorm to greet us. Heavy rain followed me on my journey home to Coleraine and some radio broadcasts warning of flooding were also noted.

Next morning was a different story, the rain had subsided but parts of the province were flooded, most notably Drumahoe, quite close to Altnagelvin Hospital. Trying to get to the Hospital was crazy with nearly every road either blocked by flooding or traffic jams.

On finally reaching the hospital I was prepared for the Biopsy, quite an uncomfortable procedure as it is done through the back passage and as I was to learn "hit and miss". My dilemma didn't end there as in the theatre the Doctor informed me that it is their policy not to take a biopsy after only one blood test. Consequently I had another Blood test done and another physical examination. This left me a little annoyed as after the horrendous journey to get there, I felt the ball was just being kicked down the road.

Next day however the Doctor rang me and said that the Blood Test had revealed another high PSA reading which he was not happy with and that I would indeed require a Biopsy. This was arranged for the following week and a few days later I received a call from the Hospital to say that the Biopsy was clear. I thought great news! Despite the procedures, uncertainty, angst I had gone through, everything was clear and I could carry on with life as normal but the symptoms remained and I was told I would be seen by the Urologist in about 3 months for a review.

The follow up

Three months came and went, then we had Christmas holidays, so it was not until 26th January 2018 that I got to see the Urologist. Once again blood tests were high and another physical examination carried out. After explaining that my symptoms had not eased, I was referred for an MRI scan. Quite soon after this appointment (6th February) I had the scan at Antrim area Hospital. This indicated that there was an area of interest on the prostate. My first thought at the time was, it is Cancer! My second thought was, why didn't they carry out an MRI scan after the second blood test!

I was then referred for a targeted Biopsy but this time it would be trans perineum (from outside) and was carried out on 27th March 2018, it involved a general anaesthetic and a day long stay in hospital. The results of this were made known to me on 13th April 2018, and for anyone who is superstitious, it was a Friday, and indeed I had cancer.

The diagnosis

When you are sitting in front of a Specialist Oncology Nurse and she confirms the three words “you have cancer”, this is what I would call the sledgehammer moment.

This is the point when a million thoughts go through your mind, how bad, is it treatable, what will the treatment be, why me.

I recall some years ago my brother informed me he had Mesothelioma (a form of Lung Cancer), that it was incurable and his life expectancy was 12 months. I thought, how does someone cope with that? Then when you are given a diagnosis yourself, how are you going to react? I was actually quite calm about it, my intuition was, from day one, that I had cancer. Possibly my career in the Fire Service taught me to be pragmatic and not go to pieces at being told bad news, take it on the chin and deal with it.

A bone scan was carried out on 23rd May to check the initial diagnosis was correct, that it was localised and had not spread.

Self research

During my career in the Fire Service I was involved in many projects involving research into new equipment, standards and advancement in procedures. This is where my experience kicked in, I started to troll the Web and find out as much information as I could about my condition.

Different parts of the UK were treating localised Cancer in a couple of different ways and one treatment that intrigued me was Brachytherapy, a procedure whereby radiation is injected directly into the prostate. With this information I felt that I would be able to make an informed decision when I met with the Oncologist.

The treatment

I was then seen for my first Oncology appointment at Altnagelvin on 21st May. I was started on hormone treatment (opting for three monthly injections) and given advice on the standard of treatment that was offered to me - 37 sessions (fractions) of radiation over five and a half weeks. The Consultant said that I would be reviewed in 3 months which got me a bit confused as I thought my treatment would start sooner than that. It was explained to me that the hormone treatment was in fact the start of my treatment and radiotherapy would not commence until three months of this treatment had been administered.

I had been doing some research into prostate cancer and treatments available so I enquired about the possibility of Brachytherapy. The Consultant advised me that Altnagelvin did not offer that treatment but I could be referred to the City Hospital to ascertain if I would be suitable.

Tuesday 10th July I had an appointment with Dr. Mitchell at the Belfast Cancer Centre at the City Hospital and all treatment options were explained:

Surgery

37 radiation sessions

brachytherapy

It was at this consultation that I first learned of the research work that was being done here in Belfast. A research project known to the Medics as a SPORT trial was in progress and because of my diagnosis (localised advanced), I may be able to access.

I was really interested if not a little selfish with the clinical trial as it would only involve 5 radiotherapy sessions over five weeks. My thoughts were that

one day per week would result in less travelling and be the least inconvenience to everyone. I was also of the mindset that without trials and research things are never going to progress, with the added bonus of the research being held in Belfast. I recall once telling someone that as a baby my mother wore a bonnet on my head, I don't wear that anymore because it doesn't fit.

The Trial

The first thing that comes to mind about a clinical trial is, how safe is it? Then you weigh up the pros and cons. I was assured by the Doctors that the standard of care would never be less than what I would receive with the standard treatment. I was also assured that I would be screened more often and have blood and urine tests carried out throughout the trial. The down side (if it could be called a downside), would be the side effects that I would experience with the 37 fractions.

I opted to undergo the tests to determine if I was a suitable candidate for this SPORT trial, which consisted of Blood and Urine samples together with an additional CT scan and MRI scan. Fiducial markers (pieces of gold) were injected directly into the prostate and a gel spacer injected into the area between the bowel and prostate. This would allow easier targeting of the cancer and protect the bowel from radiation. When I received the phone call confirming that I was accepted onto the trial on 29th August with my treatment starting on 17th September, I was overjoyed. By the way, it doesn't seem like it but that was a year ago last week.

The treatment

Five weeks seemed to pass in a flash, the Radiographers were fantastic, they all made you feel as if you were the only patient there when in fact there were about 400 passing through the cancer centre every day. Before each treatment I was seen by the Doctor, had blood tests taken and of course the obligatory questionnaires to complete. During the treatments the Doctor was with the Radiographers who were operating the machinery so I knew I was getting the best treatment possible.

On occasions at the Cancer Centre I met other men who were being treated with the 37 fractions and listening to the hardship and tiredness they were experiencing attending for their treatment. At one stage I actually felt a little guilty that I wasn't having the hardship they were experiencing.

I had little side effects from the treatment other than what would normally be expected, I did get tired some afternoons but after a power nap energy was back to normal. I did and still get hot flashes due to the hormone treatment. I do get sleepless nights.

For me the trial was 100% successful, I had little adverse effects and was able to carry out my recreation almost as normal (I am retired from full time work).

Conclusion

The Trial I am undergoing will not help or make life easier for those men I have spoken to and undergone the standard treatment but I sincerely hope that it will influence how not only treatment but diagnosis will be carried out in the future.

One major outcome of this research is in the way a Biopsy is taken. I have had three taken, two at Altnagelvin and one at the Belfast Cancer Centre. The first was a per rectal procedure which was quite a discomfort (I'll not go into the full details here), second was a targeted procedure under general anaesthetic, don't recall much about it but required a day stay in Hospital. Due to a general anaesthetic being administered, I had to undergo an assessment a week beforehand to determine if I was fit and healthy enough to undergo the procedure. I know at least one man who was put back for a month as he was determined unfit to undergo the anaesthetic. What a worry that must have been for him. The third at Belfast was again a targeted procedure, which I have been advised was the same as the second but only under mild sedation and a local anaesthetic, it was over in about 10 minutes, painless and without discomfort.

People often think about the Medical Profession, of only what they see in front of house i.e. doctors and nurses, whilst I would in no way diminish the great work that they do but there is another side to be considered in effective treatment.

When I was given my start date for treatment it was explained that it was provisional and depended on a range of specialists including: Doctors, Radiologists, Radiographers, Physicists, Researchers, to name but a few. To get to the stage of clinical trial requires a lot of groundbreaking work being

carried out in a Laboratory and may involve many hours and years of painstaking work. To have this centre of excellence based here in Belfast is testimony to the skill and dedication of the staff at Queens University and the Belfast Cancer Centre.

Without the research and innovation of people involved in the Medical profession time and cost consuming treatments will be the only options offered to men diagnosed with prostate cancer. My treatment worked for me but if I hadn't been a suitable patient, then either Surgery or a protracted treatment involving: travel to the centre (and the cost involved), possibly time off work, extra burden on the staff of the Cancer centre.

With about 12,000 deaths per year (30 per day), in the UK (research indicates this figure will rise), it is only with further research that early diagnosis and treatment can be found. The first question people ask me when they have been told of my cancer is: how did you know? what were your symptoms? Unlike other forms of Cancer, which may be detected by self examination, prostate cancer can only be determined in the laboratory, however if men act on cursory symptoms, early detection can be achieved.

PSA blood tests are an indicator but inconclusive, perhaps some time in the early future a more reliable non invasive test can be found, but it is only through research.

If I was asked to give any advice it would be:

Don't leave it too late, if you are having the classic symptoms, go and get yourself checked out. I have spoken to some men who went and saw their Doctor and found that it was nothing more than an infection.

The other advice I would give is don't go to a Consultant on your own, take someone with you. People often dwell on a particular piece of information, and maybe mulling it through their mind when the conversation has moved on, resulting something being missed.

If you are worried or concerned about your diagnosis, talk to someone, there is a lot of help out there.