My advanced prostate cancer experience

GEORGE MICHAEL FLANNIGAN

Mr Flannigan gives a personal account of his diagnosis with prostate cancer and a vivid description of his experience of chemotherapy.

On reading ‘A tale of four prostates’ by Roger Kirby, John Anderson, Sean Vesey and Damian Hanbury, describing their experiences with prostate cancer, those of us who are their contemporaries must have felt the statistics were in our favour. But we were wrong. The statistics apply to the whole population – the sad coincidence of our colleagues’ pathologies does not exclude any of us. Although it might make us wonder if the coincidence could be linked to some experience or environment that we have all been exposed to as urologists.

EARLY WARNINGS MISSED

Should I have taken more notice of the two years of muscle pains I blamed on statins? When my finger nails became yellow and brittle and I developed koilonychia (Figure 1) should I have reassured myself that it didn’t matter because I had a normal blood count? I was unaware of the colour change in my nails until the treatment made it normal. Was it wrong to relax because my PSA was steady at 1.3 in March 2014? When my flow rate began to deteriorate and I developed nocturia, should I have taken more heed?

In January 2015 I tore my hamstrings in my left leg while moving a mattress. My orthopaedic colleagues told me it would recover in two weeks – two months later it was still a problem. Around that time I noticed another pain on sitting up in bed and thought I must have also developed a left inguinal hernia. In late March I discovered I had a residue of 80cc in my bladder and microscopic haematuria.

On 3 April 2015 a colleague found my prostate felt relatively normal, but the seminal vesicle on the left side was firm. He arranged a PSA and planned a flexible cystoscopy and CT scan. The CT showed I had a fractured pelvis. My PSA came back at 13.5. The MRI showed the prostate was enlarged and there was extra capsular spread into the perineum and seminal vesicle. There were tumour deposits in the left anterior and posterior pubic rami, the right anterior pubic bone, the right sacral segments 3,4,5 and the left ilium.

The poor prognostic factors were my relatively young age (63), the low PSA production, and a subsequent biopsy

Figure 1. Discolouration and spooning of the nails (koilonychia) should have been early warning signs that something was wrong

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showing a Gleason 4+5 tumour. I thought I’d be dead by Christmas.

But I have missed out the best bits. I must have carried out 15,000–25,000 flexible cystoscopies in my life. I always thought it a straightforward and simple process – wrong again. I had severe strangury and explosive haematuria and pain for three days afterwards. During those three days I had a prostate biopsy. Although very painful at the start, the local anaesthetic worked perfectly and I had no side-effects. That weekend my wife and I felt very alone.

The following day I was told my Gleason score and started bicalutamide. On 16 April I injected my first dose of leuprorelin. Seven days later the bone pain had gone and I was walking normally for the first time in four months. I thought I might survive past Christmas. I had planned to live to 90, so I had 26 years of fun and laughter to fit into the next one to two years. We all know we will die, but it is nice to have a timetable (unexpected incidents allowing).

CHEMOTHERAPY BEGINS

On 7 May 2015 I faced my first cycle of docetaxel with ondansetron for nausea, dexamethasone for potential allergic reaction to docetaxel, domperidone for poor gastric transit, tamsulosin for bladder outflow obstruction, and Gaviscon, ranitidine and pantoprazole for indigestion. I would like to have taken paracetamol and ranitidine and pantoprazole for indigestion.

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I chose to have scalp cooling to try to keep the little hair I possess. Initially I felt this was unnecessary, but later had a change of heart. My mother was 92 with Alzheimer’s and lived 250 miles away in Scotland. She barely recognised me normally, so without hair there would be a problem. Four days after my second chemotherapy, the police had to break into her house and found her lying on the floor. She had been there 48 hours, and luckily had no serious injuries, but was in acute renal failure. But she still recognised me. Sadly, she died four weeks later.

Scalp cooling is severely painful for the first 10 minutes. I found 1g paracetamol and 100mg diclofenac one hour before helped, and it is a delight to stand under a warm shower afterwards to melt away the icicles. The reminder of each treatment day passed with few problems. I quickly discovered that the domperidone, ondansetron and pantoprazole had more side-effects than benefits, so I stopped taking them. The side-effects of dexamethasone include mood drop, tiredness and feeling fuzzy all day. There was also bowel dysfunction from the docetaxel.

Throughout four months of chemotherapy I managed to work two days a week, play golf on good days and gradually found food that was palatable. Maintaining hydration is essential. I had periods of lethargy that would pass within two hours. After my first cycle of docetaxel the bone marrow depression resulted in a neutrophil count of 0.12. A mosquito bite on my leg gave me septicemia (Figure 2). I was admitted to hospital within three hours of developing a fever and started on intravenous antibiotics. Within 24 hours I had fully recovered, but had been close to having septicemic shock and ending up in intensive care.

The leuprorelin and bicalutamide have caused weight gain and a bonus of not needing to shave every day. It felt as if the side-effects from the docetaxel were cumulative: my buccal mucosa felt rough and I used that as an indicator of its duration of action.

On bad days I felt as if my brain was in cotton wool, my legs belonged to someone else and the rest of me had flu without a fever. My teeth ached and my tongue hurt. It’s like having a hangover and flu at the same time, but without the alcohol. If a
neutrophil count was normal I was allowed paracetamol, usually with immediate relief. I assumed that tissue destruction and the release of pyrogens was causing this; I hoped it was all prostate necrosis. At four months since the start of chemotherapy, my muscles had all wasted away. My legs didn’t feel very strong and I took great care walking, partly because of that and partly because of the numbness in my feet.

I had difficulty controlling my body temperature, especially at night. This has persisted, so far, for six months since the end of chemotherapy. I find bedclothes too hot and no bedclothes too cold. I feel an ache on the back of my neck and discover the skin is very cold. My ankles still swell up and the peripheral neuropathy persists. The discolouration is clearing from my nails and I have characteristic bands for the three courses of chemotherapy (Figure 3).

LOOKING FORWARD
Two months after the end of chemotherapy I could taste and enjoy a glass of wine again. Radiotherapy was effortless with no definite side-effects. Six months after the start of treatment my PSA had fallen to 0.08; 10 months after the start of chemotherapy my PSA had fallen to 0.02. I am now working out in the gym and getting my strength back.

It’s a peculiar experience to think there is something else alive within you over which you have no control and you are merely an observer. It’s as if some kind of worm is wandering around inside you and the chemotherapy has sent it into hibernation. Let’s pray for a long winter.

Read Mr Flannigan’s blog at www.myadvancedprostatecancerexperience.com.

REFERENCE