

Part 1 – Prostate Cancer

I was referred by my GP almost exactly one year after I had retired and diagnosed with aggressive Prostate Cancer (Gleason Score 9) two years later in June 2015. It appeared that the cancer was contained within my prostate, so I opted for radical prostatectomy surgery rather than radiotherapy. Unfortunately, the surgery didn't provide a cure.

In a further attempt at a cure I agreed to two years of hormone deprivation treatment along with 20 sessions of radiotherapy to where my prostate used to be. About halfway through the radiotherapy sessions I noticed unpleasant side effects, affecting my bladder and bowel (see Part 2). Unfortunately, neither the hormone treatment nor the radiotherapy produced a cure, as immediately after the two years of hormone treatment my PSA level started to rise again.

There have been many more twists and turns in my treatment journey, including pelvic surgery to remove lymph nodes. But it was all in vain as I was told in 2019 that my cancer was incurable. I am now on permanent hormone treatment in an effort to hold the cancer at bay for as long as possible.

Part 2 – Pelvic Radiation Disease (PRD)

From the end of my radiotherapy treatment to the time of writing this (September 2020) I have been plagued with very unpleasant bowel and bladder problems, as well as mental health difficulties.

Bowel The 'proctitis' became steadily worse with symptoms such as increased frequency, urgency, tenesmus (feeling like I had not emptied my bowels), and variable stool consistency. This culminated in a horrendous period soon after radiotherapy where I was emptying my bowel 5 or 6 times a day, accompanied by very strong pain each time, as well as bleeding. After a few weeks, the extreme pain subsided but I was left with ongoing pain, discomfort and inconvenience. Eventually, 7 months after my radiotherapy, I saw a gastroenterologist who suggested my excessive wind could be caused by bacterial overgrowth (SIBO). This was confirmed 3 months later, but antibiotics did not work, and I still live with SIBO every day.

In January 2017, I told my oncologist that my bowel problems showed no evidence of any improvement. She seemed to finally understand that I was becoming increasingly upset. By this time, due to my deteriorating mood and anxiety, I had been prescribed anti-depressant medication by my GP.

I was put in touch with a colorectal nurse specialist who was involved in setting up a service for patients with 'late effects' (PRD) symptoms. At last I'd found someone who was interested in my ongoing plight, and who could offer some helpful advice.

Bladder The symptoms of radiation cystitis appeared in the second week of radiotherapy. I had greatly increased frequency, urgency, and severe discomfort, and this escalated quickly to a level which was still adversely affecting my life 6 months later. Eventually I saw a urology nurse who was extremely helpful and confirmed that the measures I was taking myself to reduce the frequency, such as 'hanging on' as long as possible, were exactly the right things to do. Since then, the urge to urinate frequently has improved somewhat; although I am still troubled by intermittent problems.

PRD Summary and what is missing from NHS services

My cancer treatment experience took a negative turn post radiotherapy, and to put it simply I have suffered, both physically and psychologically, ever since. Firstly, my distress has been greatly compounded by the lack of adequate information prior to the radiotherapy treatment about the possibility of unpleasant, permanent after effects. Secondly, when I saw my oncologist 4 months after treatment, and explained my symptoms, she seemed unsure of what to do next. I feel doctors, who must

be aware of possible after effects of radiotherapy, should be prepared and have a plan of action already in place. Seven months is too long to wait to see a gastroenterologist when your symptoms are so bad that you cannot leave the house.

There seems to be a genuine lack of support for people like me who, while their cancer has been treated, have been left with unpleasant, ongoing after effects with a potentially serious negative impact on their future quality of life.

After some searching, I did find two important sources of help. Maggie's in Dundee has been exceptional in terms of helping with my mental health. The Pelvic Radiation Disease Association (PRDA) is an invaluable 'ray of sunshine' in my bleak landscape, where I am able to receive advice, and discuss the symptoms of PRD with people who understand and empathise. It really helps to know I am not on my own in experiencing these problems.

Part 3 – Life After Treatment (Living with Cancer)

Quite clearly cancer has had a serious negative impact on any plans me and my partner had for our retirement. The ultimate diagnosis of my now incurable cancer has been, and remains, difficult to deal with. Cancer and the treatment processes have caused substantial psychological impacts as well as taking a lot of our time in visiting hospitals, making it very difficult to have much life away from home. But the most life-limiting factor has been the Pelvic Radiation Disease.

PRD adversely affects me every single day due to having a permanently damaged bladder and, more significantly, bowel. Some days I find it difficult to contemplate leaving the house, but every single day I have to plan everything around how my bladder and bowel might 'misbehave' that day. This is ongoing and will continue with me forever.

It's not all doom and gloom though, as I have managed through determined perseverance and downright bloody mindedness to get out and about more, including spending more time with our family.

I have been volunteering as a trustee with PRDA and have helped raise awareness of PRD across Scotland. I had found PRDA in my 'darkest hours' of searching the internet for help, having been told that what I was enduring was "very rare" and "very few people report back with these problems". I've since learned that the truth is very different. I became a PRDA Trustee in 2018, and my main motivation is to be an enthusiastic and active advocate for raising awareness of PRD amongst the medical profession, and with patients. I represent PRDA at organised events, where I speak about the ways PRD has impacted my life. I hope to be able to do much more of this in the future as I feel it's a particularly personal way of getting this very important message across.



In 2018, I 'found' sea/touring kayaking, which I enjoy on local lochs, rivers and off the West Coast of Scotland. I can't walk or even stand for any length of time without my bowel becoming very uncomfortable but kayaking is all done sitting down! It provides me with good exercise, fresh air, and a whole new set of friends.

When I'm on the water in my boat I feel 'normal' and can, for the most part, forget my troubles for a wee while.