Dear

Prostate radiotherapy - badges and a full bladder!

I am writing to you as a man who has prostate cancer. I recently received radiotherapy at Weston Park Hospital in Sheffield - a good service from skilful and kind radiotherapy staff. I now await the outcome.

My Story

Everyday I turned up with a full bladder and an empty colon, and waited in some trepidation for the preliminary scan prior to the treatment.

While sitting waiting in the 40 minutes or so prior to the scan/radiotherapy us men - all with the same problem, would chat and talk, often about our concerns regarding hitting the Full Bladder/Empty Colon (FBEC) target - but more generally about living with prostate cancer.

While there are formal support groups available; like many, I have felt no need to join these. This informal gathering became our support group.

As my treatment progressed I was also surprised at how some men struggled to achieve the FBEC target - which led to repeat visits to the scanner and in some cases to additional days of treatment being added to their programme. Responses to this were warm and supportive, I found this informal support really helpful - and I imagine many of the other men did so too.

The badge

In recognition of this informal support I have produced the attached badge.

I think this badge signals some important things.

- · It celebrates our common bond and experience
- It provides a gentle nudge that it is ok to talk about this.
- It can strengthen the bond between technical staff and the patients it can be worn by both!
- · In a small way it raises the profile of this important treatment to others

The lapel badge is deliberately small so that it is not declaiming or pushing this agenda - or potentially exposing someone to unwanted attention. I would also say that it is wryly funny - humour was important to us as we sat and waited.

I think it should be made available to men who are starting or are in treatment, and to radiotherapy staff. I think it could go with a small leaflet - one page only - that explains a bit more about the treatment process. This leaflet would be even stronger if it is based on what men have said and it should be easy to read! I attach an illustrative draft as an addendum to the letter.

I am not trying to make money from this. Although, covering the cost of making the badges would help!

I am very interested in collaborating with hospitals and others to take this forward

Please do respond using the email above.

Best wishes

Mark

Addendum

I think that a leaflet like this - could be available next to a little bowl of badges.

Three things I learnt as a patient receiving radio therapy for my prostate cancer.

1. Full Bladder and Empty Colon.

When I started treatment I did not understand how important this is. Basically there are two organs the bladder and the colon that change their size all the time. When their size changes they push other organs that are nearby into a different space in the body. It is crucial for the radiotherapy to work that the landscape around the prostate is the same every time radiotherapy is used. The best way to achieve this is to have the bladder always full and the colon empty. It would be much harder to achieve this the other way round!

2. A wet sponge.

The easiest way to have a full bladder every time is to arrive like a 'wet sponge'. That means that any water that is drunk cannot be taken on in the body. So, when you have a drink during 'drink time' our body has to get rid of some water and it fills up the bladder up. It actually can make things harder having a coffee before hand.!

3. Other men like me.

I quickly found that it was always worth chatting to the other men waiting for radiotherapy - they were all going through the same treatment and worries as me! I appreciated their support, humour and shared concerns. I was glad they were there!

If you would like one - please take a badge from the bowl and join the FBEC club!

Mark - a prostate cancer radiotherapy patient.