

A partner's perspective

It was a very normal, lovely spring day, but I could tell from the look on my husband's face that something wasn't quite right. We had someone doing some work outside and Ray spent most of the afternoon with them. After they had gone he told me that there was blood in his urine. I gave him a jug for the next wee and I was shocked to see that it looked like neat blood with what looked like clots in it. Our GP surgery was by now closed, so we called NHS Direct and they advised we should go to an out of hours practice. We took a sample, but they told us to go to see our GP first thing next morning.

We did, and our GP pulled no punches. He told us that he believed Ray had bladder cancer, but he expected it to be treatable. Although I have so much respect for our GP, it was still like a punch in the chest. He said that there would be a two week referral to see a specialist. There was a problem with the equipment at the hospital we should have gone to, so Ray was referred to New Cross.

The first cystoscopy took place in the outpatient department at New Cross and this was my first experience of many just sitting and waiting. It was very hard just sitting there, not knowing what was going on or what was being said. I am a fairly strong woman, but I had absolutely no control over the situation and I felt helpless. I guess I was panicking inside... at this stage I had no idea how bad the situation might be or whether it was life threatening. Eventually Ray came into the waiting area and we then went to see one of the nurse practitioners who patiently explained the situation to both of us. I was very grateful to her and felt included in his care, at this point.

There were lots of tests before Ray went in for a GA and removal of his bladder cancer. He was diagnosed with aggressive bladder cancer and this was five years ago when he was 65. But it wasn't muscle invasive so from that perspective we were lucky.

Since then Ray has had BCG treatment and also Mitomycin. He has regular flexible cystoscopies and also rigid cystoscopies under GA.

As a wife I find it very hard having no control or input with Ray's treatment. He is a private man and he would not want me to watch him having a cystoscopy, so I have no idea what happens when he is in the treatment room, either as an outpatient or an inpatient. I have to rely on what he tells me and I sometimes think that he is careful with what he says as he wants to protect me.

Living with someone with bladder cancer isn't easy. We have always loved our holidays, but we now plan round when we believe there will be routine checks. There have been a number of incidents where he has had blood in his urine, post surgery of course, but also in between cystoscopies. It seems that I spend my life asking him if he is bleeding! Which, of course, he isn't! I am sure I must get on his nerves! But, I am always expecting his bladder cancer to return. I know that it probably hasn't, but I also know that it could. It is like a black cloud just sitting there waiting to burst.

His bladder cancer is now part of our lives - it seems like there are 3 in our marriage, Ray, me and New Cross urology team! What I can say is that New Cross Hospital, and especially all those involved with the urology team and those organising and carrying out the tests, that his care has been excellent.

To date, and fingers crossed it continues - his care and treatment happens like clockwork. We sit at home having a coffee and one of us will say 'I think a cystoscopy is due' and a brown envelope drops through the letterbox within a few days!

Barbara

