

The doctor as the patient: receiving bad news

This article, written by a GP working in the NHS, gives a unique insight into the experience of being a urology patient and some thoughtful advice on 'breaking bad news'.

Day 1. Alarm bells ring. It's spotting an email from my GP the day following my prostate specific antigen (PSA) blood test. I hesitate before opening the message as thoughts flash through my mind about the patients I have known with cancer of the prostate. It makes me feel apprehensive. Is it now my turn for bad news?

"I'm afraid your PSA has come in at 9.3. This is obviously of concern and needs acting on. Would you like to come in for an examination? Let me know when would be best for you and I'll get you booked in."

I do a quick online search to find out that my risk of prostate cancer is around 25% with a PSA between 4 and 10, but the risk rises to 50% above 10 [1]. It feels unsettling. I try to think about it the other way around, that I have a 75% probability it will be benign prostatic hyperplasia (BPH). But I can't shift my unease.

I arrange to see my GP later that day. He listens to my story, checks my urine and reassures me my prostate is smooth. He suggests that, in view of the long history, it is likely to be BPH, but to be on the safe side to repeat the PSA in a few weeks. And if still raised he would do a referral to urology following the locality guidelines, on the fast track two week wait pathway (2WW). I feel a bit dismayed. I would have preferred the referral was done immediately, but I do not want to cause any disagreement. I return

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home optimistically thinking my healthy lifestyle has reduced my risk factors:

- I am slim and keep fit. The Norwegian study of 950,000 patients showed a 9% increased risk of prostate cancer in men with a BMI >30 [2]. I have always eaten healthily with plenty of fresh vegetables and wholegrains, and only eat meat occasionally. But for those who eat a significant amount of processed foods "the westernized dietary pattern is associated with a higher risk of prostate cancer" [3].
- I have never smoked, whereas "smokers had an increased risk of fatal prostate cancer of 24% to 30% for the heaviest smokers" [4].
- I do not have a family history of prostate cancer, but for those with a family history there is a 68% increased risk [5].
- I am not aware of any contact with benzene, toluene, xylene and styrene which are prostatic carcinogens [6]. Farmers with substantial exposure to pesticides appear to have a two-fold excess risk of prostate cancer, although I have used weedkiller once or twice a year in the garden [7].
- I have never taken anabolic steroids [8]; in animal studies using rats, there is clear evidence that testosterone can induce prostate cancer [9].

- It is widely thought that environmental pollution can alter the cellular hormonal homeostasis and promote prostate carcinogenesis [10].
- I have not had prostatitis; a meta-analysis provides the statistical evidence there is a significant association between prostatitis and prostate cancer [11].
- I cycle regularly wearing padded cycle shorts and use a bike saddle with a central relief channel to reduce perineal pressure. Cycling increases PSA by an average 9.5% [12]. But, on the other hand, cycling 25 minutes on average a day reduces by 30% the development of advanced prostate cancer, and you are 25% less likely to develop fatal prostate cancer [13].
- I am Caucasian which gives me a prostate cancer life-time risk of 1 in 8, compared to 1 in 4 for Black men and 1 in 13 for Asians [14].
- The risk of prostate cancer rises with age from 1 in 54 for ages 50 to 59 to 1 in 19 for ages 60 to 69 (my own age group), and 1 in 11 for men 70 and older [5].

Over the last few years, I have experienced lower urinary tract symptoms, principally needing to pee more often, both during the day and at night-time. I mentioned it to my

GP in 2016, who found a smooth enlarged prostate and my PSA was at the higher end of the normal range. In the midst of the Covid pandemic I put off making another appointment as GPs and hospitals were so stretched. But my symptoms progressed, particularly after driving for a couple of hours. I would have the feeling of urgently needing to pee. I could hold on until the motorway services and when I reached the loos, feeling desperate to go, nothing happened. I would shut my eyes and let out a heavy sigh to try to relax the prostatic spasm, eventually as the hesitancy eased a few drops would become a slow trickle. And profound relief. I could foresee one day I would go into retention.

Day 30. The day after my repeat PSA, I receive an email from my GP. "Your PSA result has come back at 6.1 so down from the 9.3 in May. It is still elevated so would certainly fulfil the 2WW criteria, but I wanted to check what you wanted before proceeding."

Day 44. I receive a hospital outpatient appointment for Day 47. This is just three days notice and clashes with my work schedule. I ring the hospital appointment number. After a long wait, listening to the choice of numbers to press, I eventually get to speak to the receptionist. I explain my need to switch the appointment date; I am abruptly asked "Why do you want to change the appointment? It is an urgent 2WW." I gently mention, "I have not had any prior notice of the date, I am a GP and on that day I have fully booked surgeries with patients who have been waiting some time and it would cause them considerable distress." "Oh . . . But we have to see 2WW appointments within 14 days of them being sent. Well . . . I can offer you an appointment four days later."

Day 51. I cycle to the hospital and lock my bicycle outside the outpatient clinic. I enjoy the ride and I feel I'm doing something to tackle climate change. The receptionist gives me a form to fill in, it's an International Prostate Symptom Score. It adds up to 21. Last week when I did one at home, I scored 20. I try to work out where I scored more. I have come prepared with a 'Three-Day Bladder Record Chart', to ensure I don't minimise my symptoms. The chart volumes are mostly between 50-100ml, and the frequency averages hourly in the day, with two to four times at night.

I read my book to calmly pass the time. After about 15 minutes I am called by the clinic nurse who leads me to the consulting room to meet the urologist. He reads the referral letter on his computer, checks

my history then examines my prostate confirming it is smooth and enlarged adding the size is about 60ml. He asks about my cycling and I assure him I use a prostate friendly saddle. He remarks that the pattern of PSA going from 9.3 to 6.1 is not typical of cancer.

I sense he might be thinking I should have further PSA monitoring for the time being, so I mention my main concern is sorting out my frequency symptoms and ask if an MRI scan would be indicated to assess if I would benefit from a HoLEP laser prostatectomy. He affirms I need an MRI with the raised PSA and a flow test, then offers the medication options. I decline. He finishes by checking with me that I agree to a telephone follow-up appointment once he has the results. I say thank you, feeling relieved I have been listened to.

Day 63. My MRI scan.

Day 72. My flow test. I read the instructions to drink plenty beforehand, but I need to time this carefully as my urgency may disrupt the test. I arrive half an hour early but have to pee right away. Then while waiting I drink a litre bottle of water. The clinic nurse provides instructions about the flow test with the requirement of peeing at least 150ml otherwise the test will need to be done again on another day. I am doubtful I can pee that much as my Bladder Record Chart best was 120ml. I sit down as this seems to help reduce my urgency and I continue to drink. After half an hour or so the urgency pain starts to build up. I have to tense my pelvic floor muscles to try to hang on and I hope that I don't go into retention. But at least I'm in the right place if I need to be catheterised. I force myself to read my book until I can wait no longer. I go to pee but it's the same as arriving at the motorway service loos. I am desperate to go but only a few drops come, then a dribble followed by a slow stream. I let out a sigh of relief as the pain of holding on slowly dissipates. I return to the nurse's office; she has the results displayed on her computer. "Yes, that's fine you've done 165ml. Now come and have the bladder ultrasound." The post void bladder volume of urine is 76ml.

Day 79. I receive a letter for a telephone appointment for Day 82 between 10.30 and 11.30. I reply by email confirming acceptance and my contact number.

Day 82. Follow-up telephone consultation with the urologist. My mobile rings at 09.00. Thankfully I am alone in my consultation room. The urologist is bright and breezy. "I thought I would ring you early before you start your day." I politely reply, omitting I

have been at work for an hour a half, going through letters and results, and have already seen six patients.

He launches into my MRI results, "The MRI shows PI-RADS3."

I have to ask him "What is RADS? I am not familiar with it."

"This is an intermediate result; the score is based on 1 being normal and 5 highly abnormal, typically with prostate cancer."

"So, what is my risk of cancer and what's the next step?"

"We need to do a prostate biopsy, these are now done under local anaesthetic through the perineum, just behind the scrotum."

"Hmmm... I'm not looking forward to it."

"I will get the biopsy organised, and you will receive an appointment in the next few weeks."

Day 98. I receive a copy of the clinic letter to my GP, regarding the telephone consultation on Day 82. "His MRI shows PI-RADS3.... Over the course of the country it equates to roughly 10% chance of prostate cancer."

I wonder if this is over optimistic as the Prostate Cancer and Prostatic Diseases 2021 report indicated PI-RADS3 is associated with a cancer detection rate of 52% [16].

Day 100. I receive a letter with an appointment for the prostate biopsy on Day 110. I have already looked online to find out as much as I can about the details of how a prostate biopsy is done and other patients' experience. I feel helpless. There is nothing I can do while waiting, except brood over the gloomy thought of being strapped into a lithotomy chair with legs astride, then scrotum taped up and a large rectal ultrasound probe inserted to guide the procedure. All while awake.

Day 110. My prostate biopsy. On the day, the two superficial local anaesthetic injections hurt far more than I expected, but soon the area starts to go numb. Then the two deep perineal injections with a long spinal needle. Initially there is no discomfort, only pressure as it goes through the numbed skin but suddenly, I wince in pain as the deep needle penetrates and keeps advancing into the sensitive area around the prostate. The assistant tries to distract me in conversation, but all I can do is take deep breaths as all the muscles in my body tense and I feel my arms shake. After several minutes' wait to allow the anaesthetic to numb the prostate, the biopsies are done, I still feel some pressure and some sharp pain. I am relieved when I am told it is all finished. I dress, drink a bottle of water and walk around hoping I

won't go into retention. I am instructed to wait until I have passed urine before I can leave. Thankfully I am able to pee.

Day 128. Letter arrives for a clinic appointment on day 132.

Day 132. Clinic appointment with the urologist. The waiting room is busy. I am unperturbed by the extra half hour wait. I have brought a book to pass the time. The nurse calls me in. The urologist is sitting behind the desk then looks up from the computer and invites me to sit in the chair opposite. I sense something is not right as he begins by recapping "You were referred with a raised PSA of 9.3 which dropped to 6, you then had an MRI with the result of PI-RADS3." Why is he not telling me the result immediately? I try to sit calmly, looking at him, and nodding when he looks up to see me watching attentively. I sense his discomfort. He barely looks me in the eye. It is not easy relaying bad news, and even more challenging with a doctor as a patient. He finally reaches "The biopsy report shows a Gleason score of three plus four prostate cancer."

Outwardly I might seem impassive, but inside, I feel my body tearing apart, fearing for the future. He asks me, "Do you understand?" I reply I have heard of the Gleason index but not what the scores mean. He continues, "This has been discussed at our MDT meeting, and your options are robotic prostatectomy or active surveillance as the risk is low. The robot prostatectomy is done laparoscopically through the abdomen, the prostate is removed completely, the bladder is joined up to the urethra, so you have a catheter for about two weeks. There is a risk of impotence of around 60% and the risk of incontinence is 5-10% which usually improves with pelvic floor exercises." He adds, "You do not have to make a decision now; I would like you to meet our urology cancer nurse who will talk to you in the next door room about our support team."

It was a shock. Even though I knew cancer was a possibility, I thought I was immune. But I felt disappointed at finding out the news this way. 'Breaking bad news' is always an emotional moment for both patient and the professional tasked with the duty. Training may improve how it is done. There are now a number of training guidelines, including SPIKES which follow these six steps [17]:

(i) Setting up the interview

I would have preferred to have been asked at the time of arranging the biopsy how I would want to receive the result. Would I want to receive the news, good or bad, in a

face-to-face consultation, and did I want to have someone accompany me? Or would I prefer to receive the news in a letter in advance, before coming in for a face-to-face consultation? This would allow time for the news to sink in and prepare me for the discussion.

When I received the letter for the appointment with four days' notice, I was uncertain if it was rapid to deliver the cancer diagnosis or just the efficiency of delivering good news.

Breaking bad news is challenging. If it is delivered in a busy clinic running late, it is unfair for both clinician and patient. I would have preferred the urologist to set aside more time.

(ii) assessing the patient's Perception

Some clinicians invite the patient to be more involved: "Perhaps you can tell me what you know so far" or "Do you understand why you had the MRI?" This introduction allows tailoring the bad news to what the patient understands.

(iii) obtaining the patient's Invitation

This gives the patient the opportunity to agree to receive information, and it may help them reduce anxiety. But some patients may shun information, in which case offer to discuss in a future appointment or with a relative or friend.

(iv) giving Knowledge and information to the patient

The urologist was thorough and factual. But I was left feeling the information could have been delivered in a more considerate manner.

Some clinicians will begin, "I'm afraid the news is not what I expected" or "I'm sorry to tell you the biopsy report is not what we hoped." Then, the professional can allow time for the patient to let this sink in, and wait until they respond, then check it is alright to continue.

(v) addressing the patient's emotions with empathic responses

The urologist did not appear to be aware of how I was reacting to the news. He continued with the factual information. He could have stopped and looked at me, then after a silence shown empathy, "I am sorry you weren't expecting this" or "How are you feeling?" or "I can understand how you feel."

(vi) Strategy and summary

I was satisfied the urologist provided me with the options and follow-up plan. He introduced me to the urology cancer nurse, who was able to talk in more detail about the next steps and provided an information pack to take home to read.

Final thoughts

I hope my story will encourage all clinicians who break bad news to reflect how it would feel being on the receiving end. There are now many training resources to help understand the challenges to improve breaking bad news through simulation training and sitting in with experienced colleagues.

I have learnt over the years the value of listening to patients and maintaining eye contact with them. Breaking bad news is not just the *giving* of information, but needs to involve a sensitivity to the way the information is *given*.

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