

My prostate story – Phil Dowd

Diagnosis

I was diagnosed with prostate cancer when I was 49. It was caught since part of my annual physical exam included PSA testing, due to family history. The initial level was 4.9 ng/mL, and a month later after a course of antibiotics (in case of prostatitis), it had gone up to 5.6 ng/mL. While I knew my levels might become elevated at some point later in life, it came as a surprise, especially since I had been feeling very well with no indication anything was wrong. At that point, a slight sense of dread came over me. While understanding there might be benign conditions that could lead to elevated PSA, my family history made me fear the worst. The doctor referred me to a specialist to investigate further, and although the digital rectal exam showed no prostate issues, the litmus test was to get a biopsy done, which at that time was not one of my favourite experiences. I elected to do it without general anaesthesia, just local, and it was mildly discomforting and just a bit embarrassing. Of the 12 cores taken, 9 came back indicating that I had prostate cancer with a Gleason score of 3+3=6. Given the spread within the prostate, my age and given family history, the recommended treatment was a radical prostatectomy. Again, I had been hoping for the best, but was mindful of family history. Nevertheless, the result still came as a bit of a shock. The doctor (Dr Bigelow) recommended that, based on age, the extent of the cancer, and family history, the best solution was a radical prostatectomy. We also discussed the other treatment options, and why they were likely to be less successful, each approach having pros and cons. I had a lot to consider on my drive home to tell family. The time after the diagnosis was definitely a bit of an emotional rollercoaster. I told my wife, we discussed further and then consulted with the doctor. That was key, as he explained his experience in the surgery, what we could expect, and it was very reassuring to us both. It was a no-brainer to schedule the surgery. We then found a time to let our daughter know, which was a worrying prospect, but one that went better than we thought. Having researched everything, we presented it very calmly that I had the problem, but that there was a solution and the doctor was very skilled, so the outcome was going to be good, just that there would be a bit of time where things could be difficult as I recovered. We then let friends outside the family know as well. Everyone was tremendously supportive, giving sympathies, but also offering to help out in different ways, and that was very reassuring, and made coping with the wait for surgery a little easier, although it was still an anxious time. Surgery took place about 6 weeks or so after the initial biopsy. For us, getting things moving quickly was helpful to do, to be able to put it into the rear-view mirror, to address it and to be able to move on with whatever was next. If we had waited and done active surveillance, I think the anxiety would've been too much to take. Ultimately, the decision was firmly based in science and fact.

Surgical clearance and prep

With the operation scheduled, I had to go through pre-surgery clearance to ensure I was able to have the surgery. This involved the following:

- (a) visit to PCP for a physical, including blood-work, EKG and X-ray. This required me not to eat the day of the blood test.
- (b) MRI imaging. This required me to have a Fleet enema several hours before the procedure. The imaging took around 45 minutes to complete and was done with and without contrast. The doctor was very happy with the imaging results, which showed that everything should be confined to the prostate.
- (c) A follow-up CT scan was required for a small lung nodule, which was determined most likely to be a prior infection. This did cause a worry, since I needed to see a pulmonologist to ensure clearance could be given for surgery (it was). I still have to have a follow-up on that to monitor (update: that appears to be fine still – not growing in size).
- (d) a Covid-19 test 7 days before the surgery.

I was then given instructions regarding preparation the days before surgery, including

- (a) instruction not to take certain medications (blood thinners, aspirin), vitamins and any herbal supplements.

- (b) bathing using hibiclens for the two days prior to surgery (available from Walgreens, they have their own (cheaper) Walgreens branded version).
- (c) going on a clear liquid diet (water, fruit juice, jello with no colours, chicken broth)
- (d) Taking a 10-oz bottle of magnesium citrate liquid at 3pm the day before surgery (again, available from Walgreens, disgusting stuff).
- (e) An enema before going to bed the night before surgery (Walgreens).

This wasn't the most pleasant of experiences and I think it left me a little dehydrated the day of surgery, something where perhaps having had a chance to have water after midnight would've helped. You may want to drink more water than you usually do to help address that.

Other prep I did: kegel exercises starting a couple of weeks or so prior to the surgery.

The Day of Surgery

This was a robotically-assisted procedure and by all accounts has been successful. The doctor said it was a textbook surgery, and when the pathology came back, the Gleason score was actually 3+5=8, but there were no issues with the margins and lymph nodes and so the doctor was confident that I was free of prostate cancer. After waking up after the surgery, I remember thinking I needed to go to the bathroom very urgently and quickly, but at this time I had a catheter, but I am not sure the pain killers had kicked in properly, it was difficult to recall clearly. It was important to hydrate quickly after surgery as the prep had left me somewhat dehydrated. It took a while to get my room for the overnight stay, but once I got the room, I asked to go for a walk as soon as I could. I did that twice, once around 8pm, once around 3am and then the next morning at just after 7am, to ensure I was breaking wind so I could be discharged as soon as possible.

Recovery

I was discharged quickly, without as much information as I'd have liked, but I had done some research beforehand. One thing that isn't really described is with respect to recovery and side effects. We were prepared for recovery, with diapers, pads and sheets as may be needed (which ultimately were not required in any large number). Also, in my research about the condition, I had found a good resource regarding surgery and recovery (available at <https://www.mskcc.org/cancer-care/patient-education/about-your-prostate-surgery>) that was very helpful and that I used as a guide. Particularly with respect to swelling issues.....

I stuck with an essentially liquid diet for the first couple of days (soups, yoghurt, water etc, but no caffeine). Drinking lots with the catheter is important to keep things flowing and allowing the colour to clear up to a nice straw colour.

I was prescribed oxycodone, but I only took two tablets, and the results were awful – lack of appetite, lack of thirst, nausea (I felt like gagging), and so I stopped and switched to Tylenol. In any case, oxycodone did not deal with the gas pain from the surgery. Only exercise and sleep/rest helped with that, and it took a few days to pass, which was a very uncomfortable period of time. After a couple of days, bowel motions began to resume, but it was important not to strain/push, and I gradually got back to a “normal” diet over a few days. Since I was not taking oxycodone, I did not suffer from constipation. I did include prune juice (a small glass a day) and fruits and veg in the diet, and things were OK. I had to be patient while in the bathroom though, no pushing! At night I slept on my back, and I used a wedge pillow to elevate my upper body. This made the roll-over and get up manoeuvre a little easier, and I could push myself up with minimal assistance. The catheter bag was supported by the bed frame, and I ensured it was empty when I went to bed.

One of the side effects not mentioned was the scrotal swelling - this gradually increased over the week I had the catheter in to the size of a small grapefruit and was awkward, as if looking like a creature on a nature program. To help with this, I did wear supportive underwear rather than loose boxer shorts but I don't know if that helped or not. I tried things such as icepacks to help. But it was somewhat disconcerting to see.

I had a large (night) catheter bag and a leg bag. I mostly used the night bag as the leg bag filled up rapidly and was kind of useless. The leg bag was OK to use for very short trips outside the house only, otherwise it was just easier and more convenient to use the large bag. With the catheter in, I drank a glass of water hourly to keep flow going and so the reddish/brownish tinge gave way to clearer and yellow quite quickly. I also tried to exercise gently, by walking around the house (at first, kitchen island, so I could support myself as needed, and then more around the house as I gained confidence, or on the patio every hour or so, but kept it light.

Eight days after surgery, the catheter came out, and the most painful thing with that was removal of the pad on the leg which held some things in place. I was driven to and from the appointment. While I had brought a diaper and a pad, I felt OK using the pad only for the drive home. Upon getting home, I had a glass of water and felt a need to go quickly. There was a small amount of leakage and so I changed the pad. I drank at a more usual rate during the day (glass of water every couple of hours) and had reasonable control with only minor leakage, but when the urge came, it came quick, and so I was glad to be home. Over the next few days, I found I was able to go longer between needing to pee, and also I worked to hold the urge and it became less immediate. This may have been due to swelling going down a lot over that next week, and the bladder may have gotten back to reasonable capacity. With the swelling going down, it became easier to exercise and so I did, gradually easing myself up to about 1 mile walks within less than a week, plus doing kegel exercises several times a day (doing sets of 10, then building up to sets of 20, perhaps 3 or 4 times per day). I kept a little diary to track my progress. Overall, I used around 6 pads in the first few days, then transitioned to bathroom tissue. I felt I could do this because I wasn't going out, but also I did establish a schedule that made me confident about going out and not having issues. After just over a week of the catheter out, I was feeling quite good and was getting energy back so that I felt I could go back to work (if I'd had a job). I was able to have job interviews though. If I did have a job, probably I would've used pads or toilet tissue but more as a precaution in case of stress issues (e.g. sneezing, coughing, laughing, suddenly standing, or straining when lifting something, or getting in/out of a car to drive), but those issues were largely OK, and I typically tried to practice a kegel exercise to prevent leakage when I was experiencing a little stress.

Generally, the leakage was very minimal, with plenty of notice of an urge, but I did find as the day went on, and I got tired, the control was good still, but not quite as good. This has gotten better over time, but I still made sure to exercise, both walking and kegels. (Note: this was essential the first month after surgery, but after about three months, was no longer quite as important, and now after almost two years is more of an afterthought). I still continued to include prune juice in my diet, along with fruit and veg, to make the bowel motions regular and easy. It takes time for the muscles to heal before you can feel confident about pushing.

After two weeks of the catheter out, I reintroduced coffee and alcohol into my diet, and found no bad effects, other than needing to go a little sooner, but coffee also helped regulate the digestive system. I could've probably done this sooner but decided not to. At about the two-week stage, I did experience some bloody urine, but only for a few (maybe 3 or 4) visits to the bathroom, and it was only lightly tinged. I believe this was due to some internal clotting/scabbing that was now dissolving after the healing process, and things became clear again quickly. I'd read about it and so it can be a worry, but it should be light only and brief in duration (maybe a day). If it gets worse, then there could be an issue but I didn't experience any issues.

Six weeks after the surgery, I had a PSA test, and the result came back that the level is negligible, below the detection limit of the PSA test. The doctor was very happy to hear this. When I recounted my urinary control, he put it down to a combination of his experience at the type of surgery (he has done over 1200 of the procedures) and also my general state of health and fitness. I do a lot of walking and I got back to doing that as soon as I could once the catheter was out, plus kegels, and it definitely helps. There are still other issues (ED), but things have started to improve a little there too, even without taking anything (update: at almost two years, it is still improving – it can take some time). It is something that can take longer to recover and one can take pills to assist too. That was not my initial focus – rather I was more worried about being embarrassed by incontinence, which proved not to be a major issue. I'm extremely happy with the choices made and where I am with

recovery at this stage. If someone had told me this is where I'd be, it would have made this more of a no-brainer that it already was. Things might not be perfect, but they are good, and I have faith that things will get better still.

In summary

- Support of family and friends was critical – there's more support there than you may think, and you'd be surprised that more people than you think have had similar issues and so are understanding. You are not alone.
- We listened to the doctor and made a very fact-based and science-based decision, trying to take out the emotion. His experience in the procedure helped put our minds at rest. The best solution for you will come from you discussing with your doctor (maybe with a second opinion as needed).
- We acted quickly to "cut it out" and that also gave us peace-of-mind.
- We followed the advice of the doctors and nurses on recovery – a big part of which is exercising – both kegels and general exercise such as walking. Take recovery one step at a time, be patient, but exercising will help a lot.