PROSTATE SCREENING, TREATMENT AND CURE – ONE MAN'S STORY

By Dr. Jim Browning

I am a 58 year old clinical psychologist whose practice focuses largely on men and men's issues. I am married with two teenage daughters. I am fit, active and eat a healthy diet. I have never had a serious illness and had never been in the hospital before 2012. In October, 2011, as part of an annual check-up, my physician ordered a PSA test which screens for prostate cancer risk. My test score was elevated, which led to further screening through biopsy. This led to a diagnosis of very aggressive prostate cancer and subsequent radical prostatectomy (surgical removal of the prostate). Initial results from the pathology report were very promising and seem to show the cancer is isolated to the prostate. Also, the first of ongoing follow-up PSA tests is "zero" or "undetectable", adding evidence that the cancer has been successfully eradicated. While I was waiting for surgery, I came across an article in MacLean's magazine (April 16, 2012) written by singer Dan Hill describing his virtually identical diagnosis and treatment. Dan described some of his emotional reactions and his internal decision-making process, which was very helpful to me as it closely mirrored my own experience. Men don't tend to talk about their internal experience, especially when it involves very private issues such as fear of death, incontinence and sexual impotence. I decided I would write my own story and make it available to physicians who have male clients facing similar decisions. Since I found factual information about the process extremely helpful, I have inserted as much medical detail as possible into the story. Explanations about the medical procedures are highlighted in italics to differentiate them from the story.

I want to thank my physician Dr. John Lebrun, my surgeon, Dr. Chris Hoag and the medical staff at Lion's Gate Hospital for the excellent care I received.

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The Call You Don't Want to Get

It is October 2011, my phone rings. It is my doctor's assistant calling to let me know that the doctor wants to see me at my earliest convenience to discuss some routine blood tests I had done as part of my annual check-up. "Here we go", I think, "they only call you in when there's a problem. Is it my cholesterol, thyroid, prostate?" When I meet with him, he says he is concerned about my prostate. My PSA score has risen from 3.5 the year before to 6.7 and the DRE (digital rectal examination) appears to show "asymmetry".

A PSA test measures the level of prostate specific antigen in the bloodstream. PSA is a marker for prostate cancer. The precise cut-off scores for "normal" PSA is dependent on your age. In my case, at the age of 58, the cut-off score for "normal" was 3.5 (the cut-off is 2.5 for men in their 40's, 3.5 for men in their 50's, 4.5 for men in their 60's, 6.5 for men aged 70 and older).Above this level, it is recommended that further testing be undertaken, specifically, a biopsy of the prostate. PSA testing is hugely controversial because heightened scores can occur for relatively benign reasons such as an enlarged prostate or inflammation of the prostate. This means that approximately 75% of men who have scores

above 4.0 and normal digital rectal exams will undergo biopsy when they don't have cancer, exposing them to an uncomfortable procedure that carries some risk of serious infection (1 in 40). Because most prostate cancer is non-aggressive or slow growing, screening also creates the possibility that, if diagnosed with cancer, a man may decide to have "unnecessary" surgery or radiation treatment; "unnecessary" in the sense that these treatments, with their attendant risks and side effects, may not actually increase their life expectancy (i.e. they will die of something else before the cancer gets them). On the other hand, prostate cancer, like breast and colorectal cancer is often asymptomatic until it has progressed to dangerous levels, but is highly treatable in the early stages. As I say, PSA screening is controversial, but given that my sister is a 23 year breast cancer survivor, my best childhood friend was just successfully treated for colorectal cancer and I have just been successfully treated for aggressive prostate cancer all because of early screening procedures, I am clearly biased in favour of screening!

My doctor says he would recommend a biopsy if it were up to him, but that he wants me to see a urologist to make that call. He refers me to Dr. Chris Hoag, who does laparoscopic surgery. I don't like the sound of this "surgery" business. After a three week wait, I see Dr. Hoag. He does a DRE and says my prostate feels fine. However, given the level of my PSA and the speed of the rise (PSA velocity), he still would recommend a biopsy. He indicates that there is a PSA test that more accurately differentiates cancer from non-cancerous etiologies, called the Free PSA test. I take this test, but book my biopsy right away anyway. I want to know for sure. The Free PSA test, which measures the percentage of PSAs that are attached to a protein molecule compared to percentage that are free (attached is bad, free is good) is not encouraging, and further suggestive of cancer. Dr. Hoag maintains that I still only have about a one in four chance of having cancer. I am not that reassured. I had been banking on a good Free PSA test, but mine is abysmal. I am pretty sure that has to change my odds.

The Biopsy Results – The Room Starts to Spin

We schedule the biopsy for three months up the road, the soonest available time. This is the only complaint I have about the medical care I received – the wait time for a biopsy was absurd given that the whole rationale for doing PSA screening is early detection. I have never had a surgical procedure done and am not looking forward to this one. Compared to childbirth, it's a piece of cake, but I 'm not used to having invasive procedures done to me. On top of that, I fear the result. My wife seems convinced it will be fine – I have always been a healthy guy and I am perfectly fit. The biopsy prep is a real treat – 24 hours on fluids, two enemas and an antibiotic. However, when I read the study posted in hospital showing that this procedure significantly reduces infections, I am happy I did it. The procedure itself takes 10 minutes. It involves inserting an ultrasound probe into the anus to get a good view of the prostate, then the radiologist applies a local anesthetic and using a needle device that sounds like a staple gun, takes 12 cores samples of the prostate. It doesn't really even hurt and the soreness goes way by the next day.

The results are ready two weeks later. I go to the meeting without my wife because I am pretty sure the results will be negative, or at the very worst, I might have one of those slow-growing cancers that takes years to develop into anything worrisome. However, I have a nagging awareness that this is one of those life situations where everything could be fine or, if not, some version of awful is going to follow! Dr. Hoag does not look chipper when he comes into the room. He does not say immediately, "no need to

worry, everything is fine" as I had hoped. Instead, he asks a few questions about how I tolerated the biopsy. Then he says, "I'm afraid that the biopsy showed that you do have cancer". He pulls a piece of paper out of a file which I can see has the words "High Risk Prostate Cancer" written across the top of the page. At this point, everything starts to move in slow motion and get fuzzy around the edges. It easily qualifies as the worst moment of my life. While Dr. Hoag is explaining my results, my mind rushes to "I won't see my girls grow up, graduate from college, get married". But, I try to stay focused on what he is explaining.

He is showing me a diagram of a prostate with my Gleason scores from the biopsy written in. *Gleason scores provide a rating of the deterioration of the tissue from 2-10 (where105 is the worst score). Each biopsy core of the prostate is given two grades from 1-5, a primary grade for the most prevalent rating (must be more than 50% of the area) and a secondary grade for the second most prevalent area (5-49% of the area). The Gleason score is calculated by adding these two grades together.* My Gleason score is 5+4 =9, about the worst you can get!

What Am I Willing to Lose in Order to Live?

He then starts discussing suggested treatment strategies. "Active Surveillance" and "Watchful Waiting" are definitely out in my case. Something needs to be done immediately. The two choices are surgery (a radical prostatectomy where the prostate is surgically removed) or radiation therapy. Being a surgeon, he confesses his bias for surgery. Notwithstanding his bias, the argument is compelling to me. Surgery and radiation have similar success rates. However, radiation can be used as a back-up treatment if surgery is not completely successful, while surgery is not usually done once radiation has been applied because of the very high rates of complications. If survival is the top priority, it isn't a tough decision, though radiation has the potential to minimize the two dreaded side-effects of prostate cancer treatment, incontinence and impotence. Also, the recovery times are quicker. On the other hand, there is a chance of collateral damage with radiation in which surrounding areas can be permanently damaged. I like the certainty of surgery, the "cut to cure" approach. I don't know enough about it at this point to make a decision, plus my head is spinning! Dr. Hoag tells me to come back in a week once I have thought about it and talked to my wife.

It really hits me on the drive home and the tears start to flow, thinking about my wife and kids without me and all the good times I will miss if this treatment doesn't work. It seems remarkably unfair that I have lived for 58 years the picture of health and now I am faced with "very aggressive" prostate cancer. I had never worried that much about prostate cancer as I had believed correctly that it was generally slow growing. Now, I have been diagnosed with something that is a different animal entirely. More tears at home with my wife, but also lots of encouragement. We initially do not tell our kids as one is away at university and we don't want to jeopardize her year. However, we come to believe that telling our kids and being generally open with people is better than being secretive. The kids are both shocked and crushed in their own way when we tell them, but both show resilience and became an important part of my support team. My younger daughter quips that it is fortunate that I am bald because if I have to have chemo, I won't have much hair to lose!

Next on the medical agenda are a bone scan and a CT scan of the abdomen and pelvis to get a rough idea if the cancer has spread outside the prostate. These tests are not able to detect microscopic migration of the cancer, but rule out visible masses (tumors). Mercifully, these tests are done quickly and a few days later, I go to Dr. Hoag's office, this time with my wife, and hear the first bit of good news. The scans were clean! Given my low PSA level (considering the aggressiveness of my cancer), Dr. Hoag is optimistic that the cancer is contained in the prostate. He mentions a 70% "cure" rate, meaning total removal of the cancer and no signs of return for 10 years. Survival rates are even higher than that (in the 90 percetiles), as you can still treat returning cancer with radiation, chemo and hormone therapies.

The Agony of Waiting for Surgery – Even Real Men Fear the Unknown

After imagining my body being ravaged with cancer for a week or two, it is a tremendous relief to start to believe that it is isolated to one area and therefore treatable. My surgery is scheduled for two months up the road (again, too long in my opinion). I am able to take a couple of scheduled holidays in the meantime, but the thought that I have a disease inside me working away is never far away. However, it helps me savour the present moment, because I'm not working with the standard longevity model any more ("I'm definitely going to live well into my 80's or even 90's" does not seem as certain).

A radical (hate that term!) prostatectomy is major surgery. The prostate sits between the bladder and the urethra. Its job is to produce seminal fluid. It also has a sphincter which governs continence in men (in addition to the pelvic floor muscles which both men and women have). In the operation, the prostate is removed and the urethra and bladder are then joined together directly. Removing the prostate, means that the man then has to learn to use his pelvic muscles to control urine flow (like women do anyway). Ninety-five percent of men learn successfully to do this, but it can take a while (3-18 months). Sexual function is affected because the nerves which govern blood flow to the penis run on either side of the prostate. Surgeons can do "nerve-sparing" surgery to help preserve sexual functioning and this is ultimately effective about 50% of the time. However, the trade-off is that the surgeon cannot take a wider margin to ensure that any cancer near the periphery of the prostate is removed. In short, you sacrifice some margin of safety for a greater chance of a normal sex life. This judgment call is influenced by the prostate risk stratification (low, medium, high risk), the suspected tumor volume (based on the number of core samples showing cancer on the biopsy) and pre-morbid sexual functioning (i.e. "Dr. Browning, how full are your erections compared to when you were 18?" Like Dan Hill, how can I remember this?). We decide based on my cancer severity and age that non-nerve-sparing surgery makes sense in terms of the cost-benefit ratio (that is, survival vs. possible "lifestyle benefits").

The surgery is better than I expected. Dr. Hoag does laparoscopic surgery in which five small incisions are made in the abdomen and the entire surgery is done without a major incision. This results in less pain and quicker recovery time. The pre-op and OR staff are wonderful, and it is oddly cordial walking into the operating room and meeting everyone, knowing that they are just about to cut a part out of me. Just another day in the office for them – they are relaxed, ("just routine"), but professional. I am out cold before I could think of a "nice place to go". I wake up in what seems like 10 seconds, but has actually been 4 hours. I am a little out of it, but I feel virtually no pain. I can't believe the surgery is over! Dr. Hoag visits me and tells me the surgery has gone perfectly and that the site looked great, meaning no

visual signs of cancer migration to adjoining tissue. Another happy moment! He has to come back and tell me again later because I don't remember the first time. My wife and kids, expecting me to look thin, pale and weak, see a pretty normal-looking husband and dad sitting up in bed. I am up walking in 6 hours and out of the hospital the next day. Back to work in 4 weeks and playing tennis in 7 weeks. I feel a great sense of relief and encouraged that I may actually have a future.

One of the challenges of the surgical aftermath is dealing with having a Foley catheter. *This is a device with a balloon inserted in the bladder and filled with water (so it can't come out easily) attached to a tube that goes through the urethra and out the end of the penis, and finally attaches to a bag. It drains urine from the bladder and the tube also acts as a stent to prevent the new opening from the bladder to the urethra from closing over (there is a new opening because the bladder and urethra are now directly connected as there is no prostate now). Catheters are uncomfortable and I can't wait to get mine taken out, but they are also not the end of the world either. If you follow the instructions for catheter care, they are tolerable. Mine is in for two weeks, which is standard.*

Great Surgical Results - Can I Hope That This Is a Cure?

The best day so far comes two weeks after surgery when I have my follow-up appointment with Dr. Hoag. He comes into the office looking downright chipper this time. First, he takes my catheter out. YES! Then he explains the pathologist's report regarding my surgical area. There was no evidence of migration outside the prostate! Clean margins! Even better, the pathologist has downgraded my Gleason ratings to 4+3 which means that the cancer is less aggressive than previously thought (though still fairly aggressive). This makes a big difference in the statistical likelihood of recurrence. I feel like someone has just handed me back my life! My wife and I stagger out of the office, feeling much lighter.

With my prostate gone, there should be no PSA in my blood stream from now on. If there was ever a positive rating, it would mean that the cancer may have microscopically seeped into the surrounding tissue and was growing again. Consequently, PSA tests are conducted every three to six months after surgery and are the primary method for monitoring treatment outcome. One hopes for a "zero" score (which will be recorded as something like <.01 or "undetectable" as the PSA test can't be that precise).

At the time of writing, I have just received my first post-surgery PSA test and it is "a zero"!

Recovering From Surgery – Dealing with Fear, Loss and Hope

Other than waiting for that zero PSA test, the focus post-surgery has been healing and re-establishing continence. There can be soreness from an operation like this for a few months. Being active, but listening to your body and not over-doing it has seemed to me to be the best approach to healing. Incontinence can be scary at first as it can feel like it's not going to get better. The vast majority of men (over 95%) will regain continence within 18 months and for most, it will happen considerably sooner. Kegel exercises done before and after surgery (but not while you have your catheter in!) can help strengthen the muscles of the pelvic floor and expedite the process. I personally found that Kegel exercises irritated my pelvis

which was trying to heal, so I listened to my body and stopped doing them for a while. I saw a physiotherapist who specializes in continence training who was very helpful in providing information and coaching me as to the right strategy. It helped me to know the anatomy of bladder function, so I knew exactly what I was trying to do and could visualize it. At this point, 12 weeks post-surgery, I am fortunate to be completely continent.

Sexual rehabilitation is generally less reliable, especially without nerve-sparing surgery and is usually the last side-effect to improve and to be a focus (It's hard to be focused on sex when you are sore and incontinent!). It can take six months to three years before signs of improvement appear and for many men there will not be a return of natural erections. However, there are a number of medical remedies and procedures that have been developed to address erectile dysfunction that can be used to address this issue. Urologists can answer questions about these options.

Living with Hope and Managing the Fear – Recovery is an Ongoing Process

For me, I am happy to be alive and most likely on the road to a full recovery. It has been a scary and stressful process, but also rewarding in that it brought me closer with family and friends. I had always been in the role of comforting others through their medical problems, but had never experienced the reverse. I was fortunate to have my wife and sister to talk to, but also a number of male friends who gave me the right combination of support and space. As a psychologist who sees a lot of male clients, I know that many men do not have close male friends. These men may find it useful to speak to a helping professional about some of their emotional reactions to the whole process and their decision-making along the way.

To be continued………

Jim Browning