Considerations re: Prostate Cancer

Last Updated: 07-Nov-2021

Check for Updates: https://bit.ly/3eBjMjg

- **Good news:** Only 1-in-4 men with elevated PSA levels have prostate cancer!

- **Before every doctor visit:** Write down your questions! Write down their answers!

- **Early Detection …** is not early enough:

  - Cancer occurs when cell division (mitosis) goes haywire. A random mutation results in cells growing out of control … and when … our immune system fails to mount an early and adequate response.

  - How many cells are required to detect malignancy? One study says 2^{24th} (~17 million malignant cells. That's a lot of malignant cells that have somehow escaped being killed by the immune system.

  - If you have one (1) lesion, perhaps all the malignant cells are confined to that lesion and there are no undetectable, microscopic, malignant cells elsewhere. Or; perhaps, not. Targeted treatments that focus on the single lesion will eradicate it and a bit of surrounding tissue, to insure that the margins are clear.

  - If you have two (2) or more lesions, you are at increased risk of having as yet undetectable, microscopic, malignant cells elsewhere – yet more cells on the path to becoming a detectable lesion. Consider treatments that address the entire prostate rather than just the lesion(s).

- **Early Intervention …** provides more options and a better outcome:

  - Watchful Waiting = **ACTIVE** Surveillance: A legitimate option for some cases, not all cases. It should only be considered after consulting with a urology oncologist. Second opinions are important before choosing Watchful Waiting.

  - But Watchful Waiting has consequences. As we get older, the available treatment choices decline and there is increased risk of side effects and/or a bad outcome.

  - A friend of a friend was referred to a urologist almost four (4) years ago. He did not keep the scheduled appointment. Quite recently he experienced a major health decline. His diagnosis: Advanced prostate cancer that has spread to his bones. The only available treatment is palliative care (to ease his pain).

- **Before every PSA test** … avoid the things that can increase PSA results:

  - Sexual activity
  - Bicycle/motorcycle/horseback riding
  - Groin injury
  - Digital rectal exam
  - Urinary catheterization or surgery
  - Biopsy
  - Supplements (diet, sports, etc.)
  - Medications (both Rx and non-Rx)
  - Recreational drugs have unknown effects on PSA levels
  - Prostate infection (Prostatitis)

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- Other characteristics that increase PSA:

    - Age
    - Heredity
    - Environment
    - Enlarged prostate

- **The typical trajectory** for investigating elevated PSA levels:

    - **Rule-out** the items above.

    - **Antibiotics;** to rule-out a prostate infection.

    - **Ultrasound;** to determine if there are suspicious lesions on the surface of the prostate and to measure the size/volume of the prostate.

    - **Option: Before agreeing to a biopsy**, consider buying better data. There are several advanced tests available, but my health insurance would not pay for them: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5153438/

        - Urologists' opinions are all over the map re: genetic biomarker urine and blood tests. For my own peace of mind, I bought a FDA-approved genetic biomarker test with a 92% confidence interval. More details regarding my choice on page 6.

    - **Option: Before agreeing to a biopsy**, consider buying a mpMRI (better than a standard MRI) to locate suspicious areas that the biopsy can target: https://bit.ly/2voGBCu

    - **Biopsy:** Typically harvests 12 cores. A pathologist will provide a Gleason Score:

        - Info: https://wb.md/39Ys0MM
        - FAQ: https://wb.md/2TlCKyn
        - A biopsy may spill malignant cells into the body: https://bit.ly/2Tnlybr

    - **There is no single "best" prostate cancer treatment.** Everyone has a different frame of reference. My best treatment; is **probably not,** your best treatment:

        - https://www.prostate-cancer.com/index.html
        - https://www.cancer.org/cancer/prostate-cancer.html

    - **Before selecting a treatment,** it is very helpful to determine if the cancer has spread elsewhere in the body. The highly sensitive PSMA-PET (CT) scan was recently approved for use in the USA after five+ years of use at 100+ hospitals in Europe and Australia. It is considerably more accurate than conventional CT scans and Bone scans. ~Half the time, PSMA-PET test results will alter the recommended treatment. Again; insurance companies in the USA will typically decline to cover this important test:

        - https://youtu.be/DNCHBVMjhtU
        - https://nyti.ms/3Ieve5F
        - https://bit.ly/3I8ViPy

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	Treatment Description	Prostate Cancer Patient Profile	Prostate Cancer Treatments	Prostate Cancer Survival Rates	Prostate Cancer Side Effects
Brachytherapy	**Prostate Brachytherapy** Minimally invasive radiation therapy implants low or high dose radiation (LDR or HDR) seeds in the prostate. LEARN MORE	**Prostate Seed Implant** Brachytherapy seeds are more effective for younger patients in good health with localized prostate cancer. LEARN MORE	**Prostate Seed Implant** Minimally invasive surgery lasts 1-2 hours with a possible overnight stay; most return to normal activities in a few days. LEARN MORE	**Brachytherapy Survival Rates** Multiple long-term brachytherapy studies have found recurrence-free survival rates of 77 to 93%. LEARN MORE	**Brachytherapy Side Effects** Possible bleeding at the minimally invasive site, blood in the urine, scrotal burning, incontinence, or impotence. LEARN MORE
Chemotherapy	**Prostate Chemotherapy** Chemotherapy may be used in advanced prostate cancer, if the disease has extended to other parts of the body. LEARN MORE	**Recurrent Prostate Cancer** Recurrent prostate cancer that has stopped responding to treatment may benefit from chemotherapy. LEARN MORE	**Salvage Chemotherapy** Chemotherapy is administered orally, or by a computerized pump, or by frequent injections at a doctor's office. LEARN MORE	**Effects of Chemotherapy** Chemotherapy may relieve pain and slow tumor growth in advanced stages of prostate cancer. LEARN MORE	**Chemotherapy Side Effects** Chemotherapy may cause nausea, hair loss, vomiting, and mouth sores. LEARN MORE
Cryosurgery & Cryotherapy	**Prostate Cryotherapy** Also called cryotherapy, this minimally invasive procedure uses needles to apply freezing gases to the prostate. LEARN MORE	**Cryosurgery Patients** Cryosurgery is used for patients with localized cancer, external radiation recurrent cancer, Gleason scores under 6, or PSA levels under 10. LEARN MORE	**Minimally Invasive Surgery** Cryosurgery takes about 2 hours with a possible overnight admission. LEARN MORE	**Cryosurgery Survival Rates** Long-term clinical results are limited but promising. LEARN MORE	**Cryosurgery Side Effects** Side effects may include moderate pelvic pain, blood in urine, scrotal swelling, mild urinary urgency, and impotence. LEARN MORE
Hormone Therapy	**Prostate Hormone Therapy** Prostate hormone therapy suppresses, blocks, or eliminates testosterone to slow the tumor's growth. LEARN MORE	**Hormone Therapy Uses** Therapy can slow the tumor's growth or lower a PSA level; it may be used before, during, or after other treatment. LEARN MORE	**Shrinking the Prostate** Surgical castration patients return home the day of the surgery. Treatment is given orally or by injection. LEARN MORE	**Hormone Therapy Effects** Hormone therapy does not destroy cancer but research has shown effectiveness in enhancing other treatments. LEARN MORE	**Hormone Therapy Side Effects** May cause impotence, weight gain, hot flashes, fatigue, loss of muscle mass; and hormone "flare" in LHRH use. LEARN MORE
Radiation Therapy	**Prostate Radiation Therapy** EBRT or electron beam radiation therapy aims external radiation at prostate cancer cells. LEARN MORE	**Using Radiation Therapy** IMRT and 3D-CRT are newer versions of EBRT and are non-invasive. LEARN MORE	**Radiation Treatment** Radiation therapy generally requires 5 treatments per week over 6-8 weeks. LEARN MORE	**External Radiation Outcomes** Multiple long- and short-term studies indicate success rates over 85% especially when used with other therapies. LEARN MORE	**Radiation Side Effects** May include tiredness, diarrhea, skin irritation, upset stomach, frequent or burning urination, and proctitis. LEARN MORE
Prostatectomy	**Prostate Surgery** Prostatectomy is the removal of the prostate by surgical incisions in abdomen or perineum, or small incisions and laparoscope use. LEARN MORE	**Prostatectomy Patients** Prostatectomy carries surgical risks and possible side effects so is usually recommended only for younger patients who are in otherwise good health. LEARN MORE	**Prostate Removal** Length of prostatectomy surgeries, recovery times, and hospital stays vary according to specific prostatectomy procedure. LEARN MORE	**Prostatectomy Survival Rates** Multiple long-term studies indicate recurrence-free success rates over 90%. LEARN MORE	**Risks of Prostatectomy** Surgical complications, impotence, or incontinence may occur. LEARN MORE
Robotic Prostatectomy	**Robotic Prostatectomy** Robotic prostate surgery is a minimally invasive procedure involving the removal of the prostate and surrounding cancerous tissue. LEARN MORE	**Robotic Prostatectomy Patients** Minimally invasive robotic surgery is reserved only for patients whose cancer is confined to the prostate gland. LEARN MORE	**Prostate Removal** During a robotic prostatectomy, surgeons remove the prostate gland through a series of small incisions using surgeon-controlled robotic arms. LEARN MORE	**Robotic Prostatectomy Outcomes** Clinical research indicates comparable surgical outcomes when compared to traditional retropubic procedures. LEARN MORE	**Risks of Robotic Prostate Removal** Impotence, incontinence, blood loss, and other surgical complications are known risk factors of robotic prostate removal. LEARN MORE
Watchful Waiting	**Watchful Waiting** Also called expectant therapy, patient undergoes careful monitoring instead of more aggressive therapy. LEARN MORE	**Expectant Therapy Patients** Recommended to those with low Gleason and PSA levels, and nonpalpable tumors. LEARN MORE	**Monitoring and Care** Expectant therapy includes regular visits to a doctor for prostate specific antigen (PSA) tests and digital rectal exams. LEARN MORE	**Watchful Waiting Outcomes** Because prostate cancer is usually slow-growing, many men opt for and benefit from watchful waiting. LEARN MORE	**Risks of Watchful Waiting** Cancer may grow between monitoring visits and quickly spread to other parts of the body. LEARN MORE
Complementary and Alternative Medicine	**Complementary & Alternative Medicine** Complementary and alternative treatment for prostate cancer explores non-orthodox modalities of patient care. LEARN MORE	**CAM Patient Criteria** The decision to explore complementary and alternative prostate cancer treatment is often a personal one. LEARN MORE	**CAM Treatment** CAM treatments include, but are not limited to, prostate cancer diets, mind-body practices, and alternative medical systems. LEARN MORE	**Clinical CAM Evidence** Clinical evidence concerning complementary and alternative medicine's role as a valid prostate cancer treatment option. LEARN MORE	**Risks of CAM** Known risk factors include lack of clinical evidence and the potential of harmful treatment interactions. LEARN MORE
High Intensity Focused Ultrasound (HIFU)	**HIFU Description** Minimally invasive procedure that uses ultrasound waves to heat and destroy affected tissues within the prostate. LEARN MORE	**HIFU Patients** Most effective for patients with Stage I or II prostate cancer or whose cancer recurs locally after radiation therapy. LEARN MORE	**HIFU Procedure** Ultrasound waves are directed at the prostate, and the temperature is rapidly elevated to ablate the affected tissue. LEARN MORE	**HIFU Survival Rates** A high percentage of men with localized prostate cancer, who use HIFU, are successfully treated while maintaining continence. LEARN MORE	**Side effects of HIFU** After a HIFU procedure, patients may experience frequent and/or urgent urination, mild discomfort, or discharge. LEARN MORE
Emerging Technologies	**Emerging Technology Description** Alternative treatments for prostate cancer are emerging from advances in technology. LEARN MORE	**Emerging Technology Patients** Emerging technologies could be one of the best options for patients who haven't responded to other forms of treatment. LEARN MORE	**Emerging Technology Procedure** Emerging technologies for prostate cancer treatment: What are they? LEARN MORE	**Emerging Technology Survival Rates** As technology advances, so do the chances of prostate cancer survival and prevention. LEARN MORE	**Side effects of Emerging Technology** Alternative healing therapies are being researched in clinical trials to find a way to treat prostate cancer. LEARN MORE

■ **Treatments Not Mentioned on the Prior Page:**

- Focal Laser Ablation: https://bit.ly/2IdvLIG
- TUSLA-PRO: https://bit.ly/3eyauof

■ **Why travel for treatment?**

- Not all treatments are available everywhere. Specialized alternatives include: Proton Beam, High-Frequency Ultasound (HIFU), TUSLA-PRO (ultrasound) and Focal Laser Ablation are only available at a few medical centers. Some treatment options will require many (daily?) visits for 4-6 weeks.

- Friend #1 traveled home, two days by car from Rochester, MN to Detroit, MI with the catheter in-place after an olde school radical prostatectomy. His description of the trip home? Miserable. He suggests delaying the trip home until after the catheter is removed; typically 7-10 after surgery.

- Friend #2 traveled home by airline from Baltimore, MD to Oklahoma City with the catheter in-place after Robotic-Assisted Laparoscopic Prostatecomy (RALP). He was very happy to be home, but it was not a great travel experience. Tip: Use **TSA Cares** to minimize the possible public humiliation of security screening: https://www.tsa.gov/travel/passenger-support

■ **All therapies have potential side effects**:

- **Minimizing side effects:** Experience matters. It matters a lot. Ask the urologists for their track records. Ask if they take everyone referred to them? Do they take the complicated/salvage cases?

- **Two Big Elephants** in the room are in incontinence and erectile dysfunction. Again; experience matters a lot. FWIW; I chose robotic surgery. My surgeon's stats over 2,770+ robotic surgeries:

  - 95% of patients dry within six (6) months
  - 97% of patients dry within nine (9) months
  - 98% of patients dry within twelve (12) months
  - 95% of patients have (some?) sexual function is restored within twelve (12) months

  - A friend recently visited a Very Big Name hospital. The surgeon's stats were:

    - 95% of patients dry within twelve (12) months
    - 60% chance of impotence

- **More & Bigger Elephants**

  - See the treatments and side effects on Page 3
  - Ask questions!
  - Take notes!

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- **Infection Control; ERAS = Enhanced Recovery After Surgery**: Numerous research reports document that ERAS practices result in fewer infections than traditional care. ERAS starts at-home, before surgery and continues in the hospital and thru recovery at home. While ERAS is mainstream in Western Europe, few USA hospitals have (yet) adopted ERAS. I asked my surgeon to write a medical order for ERAS-like care while I was hospitalized and he indulged my request:

  - https://bit.ly/2Pz3iem
  - https://bit.ly/2TgYhrO

■ **The tenor sings tenor.** Surgeons, cut. Radiologists, radiate. Talk with multiple urologists, preferably with different institutions, to insure that you get perspective that is not biased by "that's how we do it here." Otherwise ...

- If your PCP refers you to a surgeon, a single specific surgery will likely be offered. There are at least three surgery alternatives. Olde school, laparoscopic and robotic. Expect a surgeon to have a strong favorite. If you choose surgery, interview multiple surgeons and discuss the alternatives.

- If your PCP refers you to a radiologist, a single specific radiation therapy will likely be offered. Each radiologist each seems to have one favorite therapy from the many alternatives (3D-CRT, IMRT, IGRT, VMAT, SBRT, Proton Beam, etc). Interview multiple radiologists. Consider asking if they have an ownership interest in the clinic they are directing you to.

- If your PCP sends you to a <InsertUrologySpecialtyHere> ... you get the idea, eh?

■ **Do not be bullied:** Beware of hyperbole and outright disparagement that is intended to manipulate:

- One surgeon told me, "If you do not do surgery, you are clinically insane." Next!

- Another surgeon told a friend that dared to ask for a 2nd opinion referral, "If you get a second opinion, don't come back." Next!

- A radiologist working at a hospital offering (only) External Beam, ridiculed a friend considering Proton Beam, advising that those seeking Proton Beam are members of a science denying cult. Yes, he used the word cult. Five years later, and now working at a hospital offering Proton Beam, he was recommending Proton Beam over External Beam. Next!

- If you find it personally unpleasant or difficult to insist on getting complete and satisfactory answers to ALL of your questions:

  - Consider delegating to a Type-A+ personality that will advocate for you.
  - Consider a new doctor. The best doctors are unafraid of peer review and discussion.

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- **Consider paying for better data** before a biopsy. Only 1:4 men with high PSA levels have prostate cancer. There are several much better tests urine and blood tests available, but my insurance would not pay for them:

  - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5153438/

  - When considering which test, the test manufacturers use a lot of very scientific sounding weasel words to describe their accuracy/reliability. Hint: Both "accuracy" and "reliability" are weasel words. Specificity and Sensitivity are technically meaningful, but fraught with statistical nuance. I suggest that you use:

    - NPV = Negative Predictive Value = the proportion of those with a negative test result ... that are indeed disease-free.

    - PPV = Positive Predictive Value = the proportion of people with a positive test result ... who actually have the disease.

- **Consider buying a mpMRI before the biopsy.** Why? To locate the suspected malignancies and target those areas during the biopsy. BCBS would not pay for this as it is not "standard" treatment. Insure that you get your own CD/DVD of the images. Both of my urologists loved having this additional information.

- **Without a MRI or mpMRI,** a urologist does a TRUS biopsy: Imagine a blind man using a bar straw, poking a loaf of raisin bread, trying to find raisins. Maybe he finds raisins. Maybe. A friend's TRUS biopsy found one lesion, but missed two other lesions found by the pathologist.

- **During a "fusion" biopsy**, a (static) MRI image is fused (overlaid) with the live ultrasound (poor quality) video to guide the needle. A skilled urologist may harvest a few additional cores from the targets of interest.

- **During a mpMRI biopsy**, a much higher quality, live video guides the needle to the tumors. Why mpMRI? https://bit.ly/384kKO3

- **Biopsy - Full sedation reduces risk of infection.** Prostate infections suck and are difficult to kill. The increased patient monitoring that comes with full sedation enables the use of stronger antibiotics than what is available if you choose twilight sedation.

- **Surgery-first, preserves the radiation option(s).** If you choose radiation-first and disease recurs, few surgeons will attempt salvage surgery. If salvage surgery is possible, it is considerably more complicated, the risk of side effects is increased and the long-term prognosis is less certain.

- **Advocacy - do NOT be a sheeple!** If you cannot do it, find someone who can. In my case, from the biopsy and diagnosis to robotic surgery was a four (4) month wait. I called the surgical schedulers 2x weekly and very politely inquired/reminded them that if there is a cancellation, I am available on very, very short notice.

  It is not (only) who YOU know. Who do your friends know? I reached out to a few pilot/doctor/healthcare friends, asking if they would inquire about moving me forward on the schedule. The prostate needs two months to heal from the biopsy trauma. My wait was reduced from four months to the minimum of two months.

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- **Collect and manage your own records:**

  - During EVERY visit, ask for hardcopy of everything the doc is reading from a screen. EVERYTHING. EVERY visit. Do not leave without your own hardcopy. Always. Paper, DVD, whatever.

  - Determine specifically who (name, address & tele) has physical possession of your pathology slides. Call the number provided to verify this information.

  - Ditto for the necessary pre-approval letters from your insurance company. Hospitals do misplace/lose records. Sad, but true.

- **Second opinions:** A second opinion is always appropriate. Be concerned if your doctor does not encourage you to seek a second opinion and offer to provide a list of recommended specialists.

  - The hospital I chose for my second opinion lamented that they could see me in three days, if only my records were not encumbered by the glacial one-month bureaucracy of the first hospital. Thankfully, I had hardcopy of all my records and emailed them immediately. But I did not have my pathology slides. Getting my slides wasted five+ hours, driving, waiting and (ahem) reminding them: **HIPAA rules require** healthcare institutions to provide your PHI documents for a reasonable fee, whenever you request them:

    - Info: https://www.hhs.gov/sites/default/files/righttoaccessmemo.pdf
    - Fees: https://bit.ly/39iexQ7

  - **Insist that a different pathologist grade your slides.** Why? An acquaintance shared:

    - The first pathology report (done locally) said, "you have cancer, but don't worry. It's not aggressive."

    - The second pathology report (Mayo Clinic) said, "you have a clinically significant cancer that will probably kill you."

    - His local urologist said, "It's hard to argue with the Mayo Clinic."

- **Consider ...**

  - ... A teaching/research hospital.

  - ... Allowing Residents to participate. They are indeed "real" docs. They have completed med school. They will probably be in year four or five of their 5-year residency.

- **Why You Should Consider a Teaching/Research Hospital:**

  - Peer review, group discussion, planning and defined roles & responsibilities. Having more big brains discussing: You, What, When, How, Why and the What-If's is a very good thing. You need a unified team with zero hierarchical barriers to effective communication: https://youtu.be/hW7LGxCLauo

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- **My Frustrations:**

  - The first hospital could not satisfactorily communicate any "plan" whatsoever. After completing a procedure, I would be told to expect a call "sometime in the next week" about the mystery next-step. And; I would learn that each next-step was 2-5 weeks in the future. I asked for a plan/trajectory and they could not provide one.

    The second hospital, during my first visit, provided a folder with a detailed itinerary for my next 12 months: Appointment dates & times, names, buildings, rooms, maps and parking.

  - Having to answer all the damn robo-calls, because I did not want to risk missing a medical call.

- **Catheter:** An inconvenience, not the horror that I anticipated. Only a few brief moments of self-inflicted unpleasantness. For the first 3-4 days I moved very deliberately as I was figuring it out. I was told that it would stay in for ten (10) days, but it was removed on day seven.

- **Meds & Supplies:**

  - Sent home with:

    - Antibiotics
    - Stool softener; zero abdominal straining allowed
    - Catheter bags
    - Tape, gauze and dressings
    - Rx for Viagra; promotes blood flow and nerve recovery
    - Rx for narcotic pain meds (that typically cause significant constipation.

  - Meds & supplies you should buy:

    - Extra-Strength Tylenol; only used for a few days.
    - Bacitracin ointment or Neosporin w/lidocaine.
    - Urine pads for bed and chairs
    - Urine/bladder pads or adult diapers
    - Butt wipes
    - Very loose clothing – sweats, over-size women's night shirts, etc.
    - Bard Statlock Foley Stabilizers; Qty 2-3. Amazon: https://amzn.to/2VKpu8d

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Exercises:

- Pre-Surgery:
  - Kegels: https://wb.md/2I2U31X
  - Pelvic floor: https://www.wikihow.fitness/Do-Pelvic-Floor-Exercises
  - Walking @ target heart rate for 30+ minutes per day: https://mayocl.in/2Pmcr9T
  - Tip: Use your smartphone calendar/reminder app to insure that you do your exercises on-time, every day.

- Post-Surgery; after catheter removal:
  - Do not (re)start exercises until approved by your doctor
  - Kegels: https://wb.md/2I2U31X
  - Walk at a comfortable pace without exertion

Other Resources:

Title: Guide to Surviving Prostate Cancer
4th Edition is current as of February 2020
Author: Patrick C. Walsh, MD
Amazon: https://amzn.to/3cjbLfw

Title: Five vital documents that you should have: https://bit.ly/2vmTcWY

Support Groups: This link will anonymize a Google search: https://bit.ly/396yBVj

General thoughts & reminders:

- Surgery traumatizes the urinary/genital systems once; the day of surgery. There is a reasonable expectation for a return of (some?) normalcy over time. Experience matters. It matters a lot.

- Radiation; whether X-ray, Proton or another alternative, creates cumulative trauma. Function may continue to decline for months before rebounding. There are very different mechanisms are at work.

- If disease recurs after radiation therapy, salvage surgery is very unlikely to be an option.

- Both the biopsy and surgery risk inadvertently spilling malignant cells into the body.

- Surgery was certainly a discomfort, but not painful.

- Attitude: On every visit, I worked to be the best, on-time, friendliest, up-beat patient that the staff encounters. A smile, a joke, a friendly inquiry and a genuine thank-you can crack open a door and possibly result in a favor being granted.

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- **Acknowledgements:** Thank you for your encouragement and sharing your experience

  - Artee
  - David & David
  - George
  - Jim
  - John
  - Luc
  - Michael
  - Randy
  - Ron
  - Scott
  - Walter Atkinson, RIP
  - Ward Miller, RIP

- **Timeline** for my Robotic Surgery; Your Mileage Will Vary

May 2: PCP referred me to the urologist down the hallway. The first available appointment was in seven (7) weeks. A drug sales/RN buddy was able schedule an appointment with another urologist only four (count'm 4) days later.

May 6: Medical history taken. PSA. DRE. Antibiotics. I inquired about ExoDx & mpMRI.

May 31: PSA test. ExoDx urine test. Ultrasound.

Jun 23: mpMRI @ 3 Telsa's

Jul 1: ExoDx results: Malignant and aggressive. mpMRI found four suspicious areas.

Aug 5: Fusion biopsy. Told I would get Gleason results at my Sep 17th appt. I asked to be called with my results when they were returned.

Aug 9: Doc called: Gleason 7 (3+4) and aggressive. First available robotic surgery scheduled for Dec 2nd.

Aug 10: I ask friends (docs, RN, Paramedic and drug sales/RN) if they have referrals. Consensus is to try shifting to a large teaching/research hospital. Drug sales/RN buddy gets me an Aug 16th appt.

Aug 14: New hospital calls to cancel my appt for Aug 16th, advising the first hospital requires 1+ month to send my records. I forward everything I have via email. I promise to somehow get the missing MRI DVD and pathology slides out of the first hospital.

Aug 15: Spend five hours prying my MRI DVD and pathology slides out of the bureaucracy and hand deliver them to the teaching/research hospital …

Aug 16: Slides scored as Gleason 7 (4+3) and aggressive. Robotic surgery is Dec 6th.

Aug 19: I query five docs about who they would want running a daVinci robot for their family member. Only one urologist is mentioned by all five. I ask surgical scheduling to reschedule with him. Surgery date slips to Dec 19th.

Aug 20: I politely begin asking for a sooner date, explaining that I am available on very short notice. I do this every Tuesday and Friday. I ask to complete the pre-surgery conference immediately in the event that there is a cancellation. I want to be fully ready. I ask to be put on the On-Call list.

Aug 23: Pre-surgery conference with admin, PA and psychologist. I learn that the prostate needs to heal for two months before surgery is possible. Earliest eligibility is Oct 5th.

Sep 6: Surgical scheduling confirms that I am #1 on the On-Call list.

Oct 5: Surgical scheduler calls on her day-off. They have a cancellation for Oct 7th.

Oct 7: Robotic surgery scheduled for 1PM is delayed until 6PM. Surgery is scheduled for three hours, takes four. Moved to an ERAS/isolation room @ 1AM.

Oct 8: Discharged @ 5PM. Told the catheter will be removed Oct 17th. Went home with antibiotics, Bacitracin, Extra Strength Tylenol and a Rx stool softener.

Oct 13: Surgeon called (on Sunday night) with best results possible - 97% chance of being PCa free for the next 10 years.

Oct 15: First check-up. Catheter removed (early). Instructions re: ED and recovery exercises.

Nov 1: Joint mtg w/psychologist & sex therapist re: my surgery, recovery and expectations.

Nov 15: First of 20 PT appts. Passed the Exit criteria on my first visit. Cancelled 19 appts.

Nov 19: Meet w/urologist; PSA is undetectable.

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- **Timelines:** Provided by others' first-hand experiences

  - External Beam: 6 weeks, 30 appointments, Monday-Friday.
    No catheter.
    Radiation block required to protect the rectum:
    https://bit.ly/2TuO4t4

  - Proton Beam; Option #1: 10 days, 5 appointments, every other day.
    No catheter.
    Radiation block required to protect the rectum:
    https://bit.ly/2TuO4t4

  - Proton Beam; Option #2: 9 weeks, 45 appointments, Monday-Friday.
    No catheter.
    Radiation block required to protect the rectum:
    https://bit.ly/2TuO4t4

  - High Dose Radiation: 2 weeks, 1 appointment each week.
    No catheter.
    Radiation block required to protect the rectum:
    https://bit.ly/2TuO4t4

  - Focal Laser Ablation: 1 day. Catheter for 7-10 days

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Contributed by a DDS/pilot friend:

My Personal Experience with Prostate Surgery at Duke University Medical Center

Suggestions:

1. Go get some big women's night shirts at Walmart. It will be easier to take care of yourself wearing that than shorts or sweat pants
2. Neosporin with lidocaine get a couple of tubes
3. Butt wipes
4. Let Duke Pharmacy fill your meds
5. Waterproof baby mattress pad – just in case
6. Bard Statlock Foley Stabilization Device – get 2 or 3 (Walmart.com)

<u>Pre-Surgery – Day Zero</u>

At first I thought the whole electronic Duke MyChart was a barrier to treatment but it actually is a great way to see all the moving parts of your treatment and get questions answered. It allows your treatment to be reliably replicated so things are not missed and you are kept informed. I didn't really want to embrace it but ultimately found it extremely useful. The nurses seem to respond quickly. The surgeon, not so much.

My treatment coincided with the COVID scare of 2020 which made things very uncertain. In fact, my original surgery date was cancelled due to the outbreak so some of my thoughts might be shaded by this event.

Travel light – you just need your photo ID, your medical card, and a credit card. Bring a book or a music device. Don't bring any jewelry. I debated whether to bring my cell phone and ultimately left it with my wife. You don't really need it. She will get automated text messages regarding your surgery and, as of this writing, wasn't allowed to visit until 1 pm to 9 pm on the recovery floor.

The day of surgery, the admission process was very efficient. The ladies I met checked me in, steered me in the right direction, and kept things moving well. If you are a Type A person, just relax, go with the flow and everything will be OK. Nothing is going to happen faster because you are impatient.

The pre-op nurses were the best. Gemma and Jeff had great bedside manners, were confident and positive and just made you feel like you were in good hands. Might as well give up all your modesty because you won't need it. Do what they tell you and don't be a jerk. You will get a useless gown, they will start an IV, and Manscaper Matt will come in and shave your belly. Say what? Yes some guy will come in and shave you from below your rib cage to the top of your groin. He did a great job by the way. If you are a hairy fellow you might want to be proactive and do it yourself. Also shave the top of your mid-thigh as that is where the Bard Statlock is going.

I had Dr. Williams as my anesthesiologist. What a great bedside manner! He'll go through his little speech and answer any questions you have. The surgeon will pop in and check on you. Dr. Polascik was my surgeon. My impression is that he is all business and very focused on the task at hand. I don't how difficult the robotic surgery is but in my experience he is very good at it.

When it is time to go, they will wheel you into the operating room, get you breathing on some oxygen and then nothing. Out like a light. Upon waking up, you are magically in your hospital room. I have no memory of how I got there.

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So my initial experience was very little pain. During the overnight stay I was impressed with the level of pain management. Between the drugs they gave me in the OR and the gabapentin, Celebrex, Tylenol and lidocaine patch, I can't say I ever had any real pain. Maybe a 1 out of 10. What hurts is the IV in the hand. I couldn't wait to get rid of that. It hurts worse than the surgery. Next worse is the tip of your penis. It gets rubbed raw. The nurses will get you some bacitracin to put on it but my suggestion for when you get home is some of the ointment with lidocaine in it.

My biggest fear was the catheter. I am not sure why but the thought of having a tube in my penis scared the crap out of me. It's not too bad. You are hyper aware that your delicate organ is connected to a tube and anyone messing with your bag or tube gets transferred to the tip of your penis. Uncomfortable and inconvenient but required, so suck it up buttercup.

You will want to go home ASAP. It is hard to relax and get rest on the floors. Although the nurses up there are great, they are going to take your vitals and your blood and give you meds and in general keep you from relaxing. So your day will be spent watching the clock or TV (nothing on really) or trying to sleep. It will be hard to focus after surgery. Your mind will wander but I felt much clearer the next day.

Your gut will feel like someone made a Jell-O cake and then squashed it. It is hard to describe but there is just a lot of tightness there like maybe Mike Tyson punched you in the gut. Getting up and down puts a lot of strain on your mid-section and you don't want to rip or pull anything so you will be hyper protective of your tummy.

I felt the post op care on the floor was excellent so just listen to the nurses and do what they say and eventually they will discharge you. The discharge takes hours. All the paperwork has to be correct so don't expect to be released quickly. It was 3 pm before I left the building. Remember that big nightshirt I told you to get. Now is the time to put it on. If you have a nightcap you can look like Ebenezer Scrooge.

Get Duke Pharmacy to fill your prescriptions. This is where that credit card comes into play. They will ask for payment and bring the drugs to your room. It will save you the hassle of getting it at your home town pharmacy or the possibility that they don't have one of the prescriptions.

Post-Surgery – Home at last!

Day One was basically figuring out what meds to take and when. I really was not having any pain. Discomfort yes, pain no. However I didn't want to have any pain and try to play catch up so I took the meds as prescribed.

One of your milestones is going to be pooping. It is very difficult to hold your catheter bag, sit on the toilet, take a crap and wipe your butt. The stool softeners and fiber seemed to work well so what comes out is baby poop. Now it is difficult to twist around and wipe your bottom. As sad as it is to say, you might have to have someone wipe your butt. You might want one of those wet wipes to finish cleaning yourself off.

And speaking of help, you are going to need it. Someone is going to have to help you. It would be very difficult to recover by yourself. You can't bend over and touch the floor. If you drop something it is going to stay there until someone else picks it up. My wife is pretty damn awesome.

So day one, your hand hurts from the IV, the tip of your penis is sore, and your belly feels like you swallowed a watermelon. There is going to be a lot of swelling which the doctors don't seem to mention. The lidocaine patches work well. They did talk about bladder spasms and gave me meds to prevent that but with the swelling and meds it is hard to know what you are feeling down there. Is it your stomach rumbling, your intestines, your bladder, your colon? It's all hard to say what is bothering you when you get a little belly rumble.

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Eat several little meals, get up and shuffle around every hour or so. I've staked out a spot on the reclining couch. I put the horseshoe shaped butt cushion that came from the pharmacy down and the waterproof baby mattress pad on that. You won't feel like doing much and you will be uncomfortable but not in pain. Try to read a book, watch TV or a movie to create a good distraction. Your goal is now healing and only time will do that so be patient.

When to stop the meds was my next question. Should I keep taking them if I am not having pain? I decided to pose that question to the doctor via MyChart. Still haven't gotten an answer . . .

Day 3 post op is more of the same. No pain, just discomfort. Staples are starting to itch. A shower was today's goal and it was harder than I expected. Lifting your arms over your head hurts. Stretching hurts.

The next task was to change the catheter tie down. At the hospital they made me watch a video. I did not pay enough attention. My advice is to go to youtube and search for "BARD STATLOCK Foley Stabilization Device - Instructions for Use" and watch that video. It will save you a lot of head scratching. Contrary to intuition, the arrow points to the patient not to the flow to the urine bag. This stabilization device is much better than the make shift one they used in the OR. Should have switched sooner than day 3. My advice would be to change it sooner than Day 3. It is supposed to last up to 7 days and I realized the pharmacy only provided me with one. Walmart.com has them for about $10 each so I ordered 2 with 2 day delivery and I'll see if I need them. Even watching the video I managed to have urine spray on the bathroom floor. ☹

Day 4 post op the all about the itch. Your shaved stomach hair is growing back. The staples are itching. If you are sensitive to the adhesive patches they used, they itch. That said, I am feeling better. Less swelling.

I've decided to name my piss bag "Free Willy". As he is my constant companion I really can't wait to be free of him. My fears included getting the tubing caught on something and what happened if I rolled over during sleep? During day 1-3 I was mainly in a reclining couch and didn't have to worry about rolling over. The 3rd night I slept in a bed and got about 6 hours of sleep and did not roll. I guess the mind's self-preservation mechanisms were kicking in. So far, none of my fears have been an issue.

Lets talk about the meds or at least the ones I was prescribed.

1. bacitracin ointment - Apply topically 3 times daily for 14 days. Pretty self explanatory.
2. celecoxib 100 MG – 1 capsule every 12 hours for 7 days. NSAID generally for arthritis which helps with swelling and pain.
3. enoxaparin 40 mg/0.4 mL injection syringe - Inject 0.4 mls (40 mg total) subcutaneously once daily for 14 days. This is your blood thinner to prevent blood clots. Not sure I really needed this but who am I to second guess the doctors. Easy to use. Pinch your love handle, use an alcohol wipe and shove the little needle in your fat roll. Needle retracts and throw it away.
4. gabapentin 100 MG capsule - Take 1 capsule every 8 hours for 7 days. Prescribed for nerve pain. Since I wasn't really having any pain I didn't think I needed this but kept taking it since my wife wouldn't let me play the "I'm smarter than the doctor" game.
5. lidocaine 5 % patch - 1 patch onto the skin daily for 5 days apply patch to the most painful area for up to 12 hours in a 24 hour period. Here I was lazy and left the patch on

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for 24 hours. Just didn't have the mental sharpness to remove the patches before falling asleep. I think they did help in preventing site pain. Starting on day 4 I just used the Neosporin with Lidocaine on the incision sites.

6. Oxybutynin 5 mg tablet - 1 tablet every 8 hours as needed (first line) for up to 14 days. This drug is for bladder spasms. I couldn't tell what I was feeling down there so I took as prescribed until day 4

7. GERI-KOT 8.6 mg tablet - Take 2 tablets 2 times daily for 14 days. Basically a laxative which I would whole heartedly suggest you take.

8. MIRALAX - Take17 grams by mouth once daily for 14 days. Mix in 4-8 ounces of fluid prior to taking. Once again a laxative to help you go.

Side effects – The only side effects I noticed were a dry scratchy throat and once a bloody nose. The nose was probably due to the Enoxaparin. Not sure about the throat maybe the Oxybutynin?

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