



Dr. Schaeffer
DISCHARGE INSTRUCTIONS

Communication with Dr. Schaeffer

Attachment 1, Potential Post Prostatectomy Problems, provides a table of symptoms, issues, and resolutions. **Should you not find a satisfactory remedy to your issue, or you need further assistance when you are home, call me at my office at 312-695-8146 or 312 695 2147 between 8:00AM and 4:30PM. My team will arrange for you to speak to me or my nurse. If you have an emergency at night or on a weekend call me on my cellular phone at 410-905-2727. If you cannot reach me call Northwestern Memorial Hospital and ask for the urology resident on call. My fax number is 312 695 7030. I can also communicate with you by e-mail e-schaeffer@northwestern.edu.**

Follow-up appointments: Call my office after you are discharged from the hospital. I typically have the catheter removed about 10 days after surgery. I will tell you in the hospital when I think it can be removed. Our first follow up will around 3 months from surgery.

- This first follow up conversation is very important because it establishes the routine for all of our future telephone calls - 3 months intervals for 1st year after surgery. (See Attachment 2, Overview of Follow-up for timing and topics for discussion.)
- These appointments will be scheduled for 15 minutes and will require your help to stay on time, since there will be another patient waiting to talk to me after we finish.

See additional follow-up information at the end of this note.

The Journey

Consider our journey as containing four (4) phases:

1. Surgery
2. The catheter
3. Continence
4. Erectile functionality

Phase 2: The Catheter Period

Where we have completed phase 1, phase 2 begins the healing process, and within this phase you need to be diligent in following the practices that will help ensure successful and timely passage to phase 3.

Medications/Prescriptions: There are 3 prescriptions you will receive before discharge. One is Oxycodone and is for pain. You may want to get that filled before leaving the hospital. Viagra is to help with return of

erections after surgery and should not be taken if you are on nitrates for heart disease. If you have heart disease, check with your cardiologist before taking Viagra. Insurance companies generally will not reimburse for more than 6 Viagra per month, so you will have to purchase some of it. Cipro is to be taken twice daily once the catheter is removed to prevent infection. Begin Cipro on the night before you are to have the catheter removed. **I usually recommend taking 3 200mg tablets of ibuprofen (Advil or Motrin) three times a day with meals for the first 5 or 6 days. (ie 600mg of iduprofen three times a day). This provides excellent pain control with minimal side effects. After 5 days, wean off the ibuprofen as this can be harsh on the GI tract. If you take Prevacid/Protonix/Nexium etc. be sure you resume this after surgery. You may take the pain pills that I prescribed for you but I encourage patients to start with ibuprofen (if you do not have trouble with ulcers) or Tylenol.**

Hospital departure: If you are traveling home from the hospital in a car, stop the car every 60-90 minutes and walk around the car to prevent the blood from pooling in the legs. If you are traveling by air, walk the length of the airplane at 60 minutes intervals. (See more on Blood Clots in Attachment 1.)

Diet: You may eat and drink whatever you wish. Alcohol consumption in moderation is acceptable. Adjust your diet so that you avoid constipation, that is, maintain a high fiber diet. See Exhibit I for addressing constipation issues.

Hygiene: You may shower after leaving the hospital.

- The water will not harm the incision or the catheter. Pat dry the incision.
- Cover the tape holding the catheter to your leg with a "baggie" or plastic wrap to avoid getting the tape wet. It is paramount that you maintain the security of the catheter. ***Should the catheter be removed prematurely, it could lead to permanent incontinence.***

Mobility/Activity: After you are discharged from the hospital you should -

- Avoid heavy lifting (more than 10 lbs.) and vigorous exercise (calisthenics, golf, tennis, vigorous walking) for total of 4 weeks from the day of surgery. After that you can gradually build up to your pre surgical level of activity but do this gradually
- Not ride a bike for 8 weeks from the date of surgery
- Take frequent short walks during the day (6-8) for 5 minutes or so (like you did in the hospital) while the catheter is in place. After catheter removal, there is no limitation on walking.
- Sit in a semi-recumbent position (in a reclining chair, on a sofa, or in a comfortable chair with a footstool), while the catheter is in place. In addition to comfort, this accomplishes 2 goals: 1) it elevates your legs, thereby improving drainage from veins in your legs which will reduce the possibility of clot formation (see below); and 2) it avoids placing weigh on the area of your surgery in the perineum (the space between the scrotum and the rectum).

There are no other serious restrictions. You may take off the support stockings 1week after catheter removal, and you may drive your car several days after catheter removal.

If you take Aspirin for you heart: If you were told to take 81mg of aspirin daily (baby aspirin) by your cardiologist (for your heart stents, etc) continue to take it. If you take it but without physician direction, I would discontinue it prior to surgery, you can resume taking it immediately after surgery. If you are on 325mg of aspirin daily, please resume taking 10 days after surgery.

Problems: Please review Attachment 1 to be able to assess and address any problems that may arise during this phase.

Catheter removal: Your catheter should be removed approximately 10 to 14 days from the day of surgery.

- On the day you are going to have your catheter removed drink a lot of fluids before you arrive at the

office. On removal day I am *only* concerned whether or not you are urinating with a strong stream. The recovery of urinary control takes longer (see below).

- ***Not having the catheter removed at Northwestern?*** It is very important for me to write to the physician that is removing your catheter. If you cannot give me the name and address while you are in the hospital, please call my secretary at 312-908-1615 and give her the information so this communication takes place ***before*** you arrive at the office of the physician removing the catheter.
- **IF YOU ARE HAVING BLOOD AROUND OR THROUGH THE CATHETER IN THE 2 DAYS PRECEDING CATHETER REMOVAL CONTACT ME THROUGH MY OFFICE. THIS MAY BE A SIGN THAT YOUR CATHETER IS NOT READY TO BE REMOVED**

Phase 3: Continence

Return to work: You can work from home when you get home.

- Most patients who do sedentary "office" activities return to work gradually beginning around 2-4 weeks from the date of surgery.
- If you do strenuous work (e.g., heavy lifting) then you should wait 4-8 weeks from the date of surgery to return.
- For those men who travel a lot for business, it is reasonable to wait 4 weeks before returning to a busy travel schedule.
- You can drive a car after catheter removal.
- You will not have your "normal" stamina for up to 3-6 months from the date of surgery, so use common sense in returning to pre surgical activity. Activities that seemed effortless prior to surgery will bring on fatigue more quickly and you may need to rest some during the day.

Urinary Control: Problems with urinary control are common once the catheter is removed. **Do not become discouraged.** Urinary control returns in 3 phases:

Phase I-you are dry when lying down at night

Phase II- you are dry when walking around

Phase III- you are dry when you rise from a seated position

In the early phases your urinary stream may be weak if the bladder is not filling, that is, most of the urine is leaking into a pad, therefore not having the needed volume. You may also experience more frequent urination after surgery as the bladder capacity increases over time. Everyone is different and, for this reason, I cannot predict when you will be dry.

- **Exercise:** To speed up your recovery, practice stopping and starting your urinary stream every time you void. To do this, you must stand up to urinate. To shut off your urinary stream, contract the muscles that you use to keep from passing gas. Until your control returns completely, wear a pad or disposable diaper. You can obtain Depends, and adult diaper, or security pads from your local grocery store or pharmacy.
- **Timed bladder emptying:** To help with recovery of urinary control, try emptying your bladder every 2-2 ½ hours, even if you do not have to go to the bathroom. This will help to keep the bladder as empty as possible, and will not fatigue the muscle needed for continence.
- **Practice without a pad:** As urinary control returns, it is not uncommon for patients to continue to wear protective pads for "security" even when they don't need them. To make sure that you do not become pad dependent unnecessarily, experiment with not using a pad when you are at home and not working. Many patients will have the sensation that they are leaking urine when, in fact, they will find that there has been no leakage on the underwear.
- **Issues:**
 - **Avoid artificial devices:** **Do not** wear an incontinence device with an attached bag, a condom catheter, or a clamp. If you do, you will not develop the muscular control necessary for continence.

- **Limit fluids:** Until your urinary control returns, avoid drinking excessive amounts of fluids. Also, limit your intake of alcohol and caffeine-both will make the problem worse. Once the catheter is removed, limit fluids to the amount necessary to satisfy your thirst.
- **Potential scar:** It is common for the urinary stream to be slower after surgery. But if you notice a progressive decrease in the force of the urinary stream this could indicate a scar. Do not wait until the urine stream is so slow that you have to strain or push to urinate. Call me if you notice a progressive slowing of the stream since simple dilation of the scar where the bladder and urethra were joined can alleviate the problem if caught early.
- **Fungal infection:** If you develop a red painful rash while urinary control is returning, you may have a fungal infection, especially if you were treated with antibiotics. This usually responds well to treatment with Lotrimin cream, a non-prescription formulation that can be purchased over the counter at a pharmacy.

Phase 4: Erectile Functionality

Erections return gradually (much slower than urinary control), and continue to improve even up to 4 years after surgery. Be patient. As I told you before the operation, the return of sexual function varies depending upon the age of the patient, the extent of the tumor (whether nerves had to be removed), and the level of sexual functioning before the operation. Men who have declining sexual function prior to surgery will have a greater chance of problems with erections after surgery. There are some patients who don't recover potency until two years after surgery. Erections return gradually and quality improves month by month with effort.

Expectations: After surgery, it is important for men to have realistic expectations of the quality of erections. At first erections will be partial and not likely strong enough for penetration. But a partial erection is success! Open a bottle of champagne if you get a partial erection because with continued effort they will get strong enough for penetration. Most men do not have recovery of an erection that is "exactly" the same as before surgery. Men who recover erections strong enough for intercourse usually have erections that are more difficult to attain and maintain, and because of this it is common for libido (desire for sexual activity) to decrease.

Tactile over visual stimulation: The stimuli for erection during the first year will be different. Visual and psychogenic stimuli will be less effective and tactile sensation will be more effective. Indeed, the major stimulus for erections during the first year postoperatively is tactile sensation. For this reason, do not be afraid to experiment with sexual activity - you can do no harm. If you obtain a partial erection attempt vaginal penetration, many patients find that erections are maintained better when upright (rather than lying down) and that vaginal penetration is easier from behind. Lubrication of the vagina with K-Y jelly can help. Vaginal stimulation will be the major factor that encourages further erections. Do not wait until you have the "perfect erection" before attempting intercourse. In addition, you should be able to have an orgasm even if you do not have an erection. With orgasm there will be no emission of semen because the prostate and seminal vesicles have been removed.

Tourniquet/"erection" rings: When erectile function begins to return many patients complain that they lose their erections when they attempt intercourse. This is caused by a venous leak. This can be overcome by placing a soft tourniquet at the base of the penis before foreplay. The purpose of this tourniquet is to retain the blood in the penis once blood flow increases secondary to stimulation. Do not worry; the tourniquet will not impede the flow of blood into the penis. My patients have told me that rubber bands, ponytail holders, or "erection rings" (which can be obtained from novelty stores) work. The best product is made by UroSciences and is called the UroStop venous flow controller. You can read about it on the web site www.urosciences.com under product information and you can order by calling the number listed on the web site.

Prescription assistance: Viagra (or another PDE5 inhibitor like Cialis or Levitra) can be very effective aid

to improve erections during the recovery period. Do not take this medication if you are on nitrate to treat heart disease (coronary artery disease). Once you are ready to begin sexual activity, I suggest that you take a 100mg tablet 1-2 hours prior to activity on an empty stomach. Do not use Viagra more than once daily.

Experiment early: It is reasonable to begin experimenting with sexual activity after catheter removal whenever you feel ready. Do not wait for erections to return on their own - they will not without a lot of persistence and perseverance on the part of both partners. Patients who are willing to continue attempts to produce erections- despite lack of a perfect erection- are more likely to have return of erectile function in the long run. Begin experimenting with erections as soon as possible after catheter removal and this will increase the likelihood for recovery in the long-term (*use it or lose it*). If you are not having success with return of erections, we will talk about other options for management during our telephone appointments.

Long-term Evaluation

Phone conversations: I would like to speak to you by phone 3 months from surgery, then 6 months, 9 months and 1 year from the date of surgery. You should have a PSA measurement done 1-3 months from the date of surgery (mail or FAX to me) so we can discuss the result at our 3-month from surgery date conversation. PSA measurement is the only follow-up exam that is needed and should be done at 6-month intervals for the first year after surgery.

Patient sharing/support volunteers: Many patients-and their wives- have told me that they would like to share their experiences with others; primarily to help other get through a stressful period. If you or your wife would like to share your experience with others, please contact my secretary at 410-502-2733. She will put your name on our list of volunteers who are willing to talk to others about their experiences with this type of surgery.

Support for Northwestern Urology/Dr Schaeffer Research: Finally, patients frequently ask how they can help support my research program here. I run a laboratory with 4 PhD researchers. Our goal is to eliminate prostate cancer so the next generation will not face this problem. For example, these projects include identifying genes that cause prostate cancer, characterizing factors that make prostate cancer progress, and implementing immunological approaches to the treatment of advanced prostate cancer.

In addition to basic science research, we also are exploring many areas of clinical investigation including how prostate cancer is inherited, who is at risk, and how these individuals can be identified earlier. Indeed, there has never been a time when research opportunities were greater.

Despite this bright future there are some clouds on the horizon. Although we have extensive grant support from the NIH, substantial private support is also necessary to maintain the facilities and the support pilot projects. There is no other institution in this country that has dedicated more resources to this effort in prostate cancer. Because all of our faculty members are full-time salaried physicians, in the past it has been possible to use the overage from patient care revenues to provide this additional support. However, as dramatic reduction in reimbursement for medical care has become a reality, additional support is necessary. For this reason, a group of patients have established an endowment campaign "Dr Schaeffer's Fund for Research and Education in Urology" to assure the long-term viability of our work. Interest from this endowment should provide the long-term stability necessary to assure that the major advances in prostate cancer are possible and will become a reality. If you would like to contribute to this cause, that would be wonderful and can be accomplished through my office, 312-908-1615.

A handwritten signature in blue ink, appearing to read "E. Schaeffer". The signature is fluid and cursive, with the first letter "E" being particularly large and stylized.

Edward M. Schaeffer, MD

Attachment 1

Potential Post Prostatectomy Problems

Symptom	Issue	Response
Constipation	Your bowel function should return to normal after the surgery (over 2-4 weeks). Note, however, pain medications can cause constipation and, therefore, should be discontinued as soon as tolerated. The rectum and the prostate are next to each other and any very large and hard stools that require straining to pass can cause bleeding in the urine.	Adjust your diet so that you avoid constipation. If you have a problem with constipation you can take Colace, an over the counter stool softener, for prevention after you leave the hospital. If you do become constipated take mineral oil or milk of magnesia. It is important to drink plenty of fluids while the catheter is in place; enough to keep the urine in the tubing (just past the catheter) clear. The urine in the collection bag will almost always be blood tinged, but that is not important as long as the urine in the tubing is pink to clear.
Bloody discharge around the catheter when you strain to have a bowel movement and/or blood in the urine.	This is not uncommon; do not become concerned; it will stop. It may arise from vigorous walking, or it may occur spontaneously. Blood in the urine usually has no significance and spontaneously resolves on its own.	Drink plenty of fluids: this will dilute out the blood so that it does not clot off the catheter and will encourage the cessation of bleeding.
BLOOD AROUND OR THROUGH THE CATHETER IN THE 2 DAYS PRECEDING CATHETER REMOVAL	MAY BE A SIGN THAT YOUR CATHETER IS NOT READY TO BE REMOVED	CONTACT ME THROUGH MY OFFICE
Leakage around the catheter	This is very common, especially when you're up walking around. The tip of the catheter is not in the most dependent part of the bladder; the balloon that holds the catheter in the bladder elevates the tip of the catheter away from the bladder neck. For this reason, when walking many patients have leakage around the catheter.	This can usually be managed through the use of diapers or other absorbent materials

Catheter stops draining completely	It is possible that your catheter has become obstructed or dislodged.	Lie down flat and drink a lot of water. If after 1 hour there is no urine coming through the catheter tubing, call me (see below).
A strong sudden desire to urinate with pain over the bladder area and simultaneous leakage of urine or blood around the catheter	This is called a <i>bladder spasm</i> and commonly occurs at the time of a bowel movement. While the catheter is in place, this is not an unusual occurrence.	You should lie down until the discomfort passes. If bladder spasm becomes frequent and bothersome, Motrin or Advil can be used to help stop the spasm. These medicines should not be used if the urine is still bloody because they could lead to clotting of the catheter.
Drainage from the wound	This can either be clear fluid (a seroma) or a mixture of blood and pus. In either instance it usually can be treated simply.	If the wound should open or the edges separates, obtain some hydrogen peroxide and Q-tips; soak the Q-tip in the hydrogen peroxide and place it through the opening in the wound to clean the open area and then remove the Q-tip. This will keep the opening from closing until all the material has drained. I suggest that you shower in the morning washing this area thoroughly (you cannot hurt it). After your shower use the Q-tip and then place a dressing or band-aid over the site. Repeat the Q-tip and dressing before you go to bed that night. Feel free to call me for further advice (see below)
Pain in your calf or swelling in your ankle or leg	During the first 4-6 weeks after surgery, the major complication that occurs in 1-2% of men is a clot in a vein deep in your leg (deep venous thrombosis). These clots may break loose and travel to the lung producing a life threatening condition known as pulmonary embolus.	If you develop any of these symptoms or pain/swelling in your leg, call me.
Chest pain (especially when you take a deep breath), shortness of breath, the sudden onset of weakness or fainting, and/or coughing up blood.	A pulmonary embolus can occur without any pain or swelling in your leg.	<i>Also</i> , you should immediately call your local physician or get to an emergency room and state that you need to be evaluated for deep venous thrombosis or pulmonary embolism. If the diagnosis is made early, treatment with anticoagulation is easy and effective.

<p>Permanently cloudy urine, or Purulent (thick) drainage around the catheter, or Continuous pain at the end of the urethra</p>	<p>Urinary tract infections (UTI) can occur with a catheter in place. With these symptoms prior to catheter removal you may have a UTI. (Drainage of mucous around the catheter is normal.) It is not unusual for some bacteria to be present in the urine. (Additionally, note that it is common to have burning with urination after catheter removal (from irritation of the urethral lining) and this does not mean that you have a urinary tract infection.) It is also common to see passage of some blood or blood clots after catheter removal and this is of no concern unless it is persistent.</p>	<p>For this reason, many urologists will place you on an antibiotic for a few days after the catheter has been removed and I have enclosed a prescription (antibiotic, Cipro) for you to take. The burning should improve within several days.</p>
<p>Sediment in the urine</p>	<p>Urinary sediment is not uncommon to see. This can be manifested in a number of different ways. Old clots may appear as dark particles that occur after the urine has been grossly bloody. There are normal substances in the urine called phosphates. They precipitate out in alkaline urine and form cloudy masses in the urine. If you see these periodically do not be concerned. This is a normal phenomenon.</p>	<p>With hydration these will usually clear spontaneously and are of no concern. Also, the pH (acidity or alkalinity) of the urine changes throughout the day. After a meal the urine oftentimes becomes alkaline. Finally, if the urine is persistently cloudy this suggests that an infection may be present (see above re UTI).</p>
<p>Abdominal pain</p>	<p>This is common. The pain is from irritation of the abdominal muscles; sometimes it is where the drainage tube exited. It will resolve spontaneously, but it is not uncommon to have sensitivity around the incisions for 3-6 months after surgery.</p>	<p>You may take the pain pills that I prescribed for you but I encourage patients to start with ibuprofen (if you do not have trouble with ulcers) or Tylenol. I usually recommend taking 3 200mg tablets of ibuprofen (Advil or Motrin) three times a day with meals for the first 5 or 6 days. This provides excellent pain control with minimal side effects. After 5 days, wean off the ibuprofen as this can be harsh on the GI tract. If you take Prevacid/Protonix/Nexium etc. be sure you resume this after surgery.</p>
<p>Firm areas or lumps in the incision.</p>	<p>You may notice sensitivity when you fasten your pants belt or a seat belt. This is normal. This is part of the normal healing process.</p>	<p>If you notice a hard area or lump at the top of the incision (near the umbilicus), this is where the suture material was tied and is also normal. It will resolve with time.</p>
<p>Discomfort in the perineum (between the scrotum and rectum), especially after sitting.</p>	<p>This common pain is coming from the area where the operation took place and will disappear with time but may be present for 1-2 months after surgery</p>	<p>Avoid sitting for a long time if it is bothersome or sit on a "doughnut" (round cushion)</p>

Discomfort in the testicles	This is very common after radical prostatectomy because the spermatic cord (attached to the testicle) is stretched during the operation.	This discomfort will disappear in time but can last 3-6 months after surgery. If bothersome, use Motrin or Advil if the urine is clear.
Swelling and discoloration of the scrotum and the penile skin	This is simply fluid that has not been absorbed by the body. It is not harmful.	If the scrotum is swollen, put a rolled hand towel underneath the scrotum to elevate it when lying down.

Attachment 2

OVERVIEW OF FOLLOW-UP

Time after Surgery		3 Mo.	6 Mo.	12 Mo.	Annually	Anytime
Update on Urinary Control		X	X	X	X	X
Update on sexual function		X	X	X	X	X
PSA blood test		X	X	X	X	X

- PSA blood tests should be obtained 2 weeks prior to scheduled phone call or office visit.
- PSA results should be faxed to 312 695 7030 attn Dr Schaeffer
- Patients may call 312 695 2147 for a Script for the PSA blood test