

Some good questions to ask

Last Updated Friday, 14 November 2008

for those newly diagnosed with non-muscle-invasive bladder cancer.

See below for Questions for those diagnosed with invasive bladder cancer

1. What kind of scope do you use;

*Straight scope

*Flexible scope?

Ask him/her if all or most of the bladder is visible upon examination. You may want to know if any pain control will be used, and if so what kind? Most bladder cancer patients find cystoscopy uncomfortable but not unbearably painful. Flexible scopes are more often used on office follow ups, while rigid scopes are used during biopsy or TUR procedures.

2. You'll want to know if the urologist is planning on doing a biopsy during the cystoscopy, or if that will be a separate procedure. You'll want to ask what sort of pain control is going to be used during biopsy;

*General anesthesia

*Spinal

*Local

*Topical anesthetic

*Sedative IV

*Other?

3. What method is the doctor using to remove tumors;

*TUR-transurethral resection/fulguration (cauterization)

*Laser

*Other?

Many times tumor tissues are destroyed with cauterization and lasers, which makes path testing impossible. This is considered a safe approach with low grade tumors. Some patients insist that all specimens be sent to pathology.

II. Q's re: Diagnosis and Prognosis

1. What is the tumor stage, grade, size, location in the bladder, differentiation?

2. Were DNA tests done and were any biomarkers analysed?

3. How may the above factors may affect the prognosis re:

*reccurrence

*muscle invasion if cancer reccurs

*cystectomy if cancer reccurs?

III. Q's re: Treatment

1. What is your treatment plan?
2. How many other people have you seen/treated with the same dx as mine? What are do statistics say about the success rate of the recommended treatment? What is your success rate with cases similar to mine?
3. Are there any other treatment choices?
4. Present your rationale for the type of treatment which your are recommending
5. What are the benefits and risks of this treatment?
6. What drugs and dosages will be used?
7. How will the drugs be given and who will perform it?
8. What is the treatment protocol (initial date, time, frequency, duration, etc.)?
9. What are the possible side effects and how should I deal with them?
10. How should I modify my diet during my treatment?
11. Whom should I contact in case there are any complications or if I have any further questions during my treatment?
12. How will the treatment affect my normal activities?
13. I am currently taking the following medicines (vitamines, minerals, herbs). Will this have any effect on the treatment?.
14. What are your feelings about the use of complementary approaches (such as: vitamins, minerals, herbs) with conventional treatment? Would you recommend any?
15. What new treatments are being studied in clinical trials?
16. Would a clinical trial be appropriate in my case?

IV. Q's re: Follow up Care

1. What kind of a follow up care do you recommend?
 - cystoscopy
 - biopsy
 - urine tests (including NMP22 urinary test 10 days follwing TUR?)
 - IVP, X-rays, other nuclear tests?
2. What life style changes do I need to make?

V. Q's re: Second Opinion

1. What are the risks of postponing the treatment in order to obtain a second opinion, and how long can the treatment be postponed without any health hazards?

2. What documentation (test results, reports, etc.) will I need for the second opinion?

3. How can this transfer of documents be arranged?

Thanks to Halina Wegrzyn for compiling these questions

Some good questions to ask for those newly diagnosed with invasive bladder cancer and considering cystectomy.

Pre Op Questions

Which technique would you recommend under ideal conditions*, how many times have you done it?

If female, how many women have you operated on using this procedure?

If male, is removal of the prostate necessary? If so, what results have you had with nerve sparing procedures?

Can the first stage of a 3 piece inflatable prosthesis be implanted during the surgery - the reservoir and pump? (helps to do it then - cylinders can go in thru small incision and be connected later)

Explain exactly what you will be doing (different for Kock, Indiana, neobladder, external).

How much intestine will be used? Will it involve the terminal ileum and cecal valve? (without the cecal valve, bacteria from the large intestine can reflux into the small intestine causing diarrhea)

What results have you had re:continence after surgery. What about hypercontinence?

Can you put me in contact with other patients to talk with about the procedure? Support group? Counselling?

Can I donate blood in advance?

Are you amenable to drug resistance tests and complying with live path specimen shipment and handling procedures during/after surgery (in case chemo is required down the road)?

How long does the surgery last? How long will I be in intensive care?

What's the average hospital stay? What is the average recovery period?

How many catheters will I wake up with, and how long will they stay in. Will there be an NG tube? For how long?

May I have the name of the anesthesiologist? (it's a good idea to discuss things before surgery)

Does the hospital have an ET nurse or an experienced staff?

What kind of pain medication is available for me post op? How will it be administered? What kind of pain medication will I go home with? How can I counteract the side effects of pain meds? (constipation)

What kind of supplies will I need when I get home and where do I buy them?

What antibiotics will I be given?

What should I do for diarrhea? (sometimes it helps to eliminate dairy products for a few weeks)

What are some of the complications that can occur during surgery?

What are some complications that can occur after surgery?

What are some of the long-term after effects of the surgery and how would these be dealt with? (possible neuropathy, impotence)

What are the long term effects of intestines holding urine, does the body adjust?

What are the long term implications for other organs, specifically kidneys?

Can you/will you check for colorectal cancer as well?

What assurances/odds are there given the stage/grade that surgery alone will be a successful therapy?

If positive nodes or signs of mets are found, will surgery be carried out?

At my stage and grade, do I have other options? Would a clinical trial be appropriate?

Post Op Questions

How soon after surgery will the pathology report be available? Will there be any biomarkers tested such as p53, p21, Ki67?

What kind of help will I need upon return home (Home health aid? Visiting nurse?), and for approximately how long?

How long will the neobladder continue to produce mucous?

Can I resume a normal lifestyle, including activities (depends on type of surgery..No contact sports, usually)?

If no spread is found, what is your planned course for follow up after surgery?

What would be my treatment options if there are signs of spread?

If a course of chemo is required, how long after the surgery do we begin? Can I talk with folks on chemo?

If female, have them explain the instant menopause or put you in touch with someone who can. This is further complicated if chemo is required because you can't tell the meno hot flash from a chemo hot flash...

What are your feelings on the subject of complimentary/alternative medicine and would you be amenable if I sought out such treatment? What kind of dietary changes, if any, will I need to make?

How often should you have a specific Vitamin B12 test run? (the routine B12 catches only 75%)

Where can I order a medic-alert bracelet? This is advised for those with internal reservoirs which need intermittent catheterization. Some examples: 'continent urinary diversion'; 'continent urostomy must insert catheter to drain'; Continent Diversion, stoma location, cath #14, q2-3 hr; 'continent urinary reservoir via stoma'; 'continent urostomy needs 16 fr catheter every 4 hours'.

*A preferred technique may be agreed upon in advance as the 'ideal' choice, however often times a person's anatomy can prohibit the creation of the preferred continent reservoir, and there is no real way to be sure until the surgeon looks inside.