

For The Newly Diagnosed

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The Patient's Pledge

- I will be heard.
- I will not be intimidated.
- I will listen to my body, my symptoms matter.
- I will be fully informed and be included in the final decision.
- I will have the best care.
- I am entitled to hope.
- I am entitled to compassion and to be treated with dignity.
- I will stand up for my own best interests.
- I will praise good care and report bad care.
- I will be safe. (anonymous)

Furthermore, patients have the right

-To be provided with all the information needed to make an informed decision about options and care, risks and benefits, possible outcomes, possible side effects, who is providing your care and costs.

-To be able to express a concern or complaint and receive a prompt response. We also have the right to file a formal grievance if not satisfied with the resolution of your complaint. For more about patient's rights:

<http://www.muhealth.org/~center/pgrights.shtml>

I've Just Been Diagnosed. What Should I Do?

- Recognize that fear is natural, and know that it can be overcome.
- Slow down the decision making process
- Ask yourself this question: Do I have trust and have confidence in my doctor?
- Recognize that your physical body needs love and attention, but so do your mind, heart and spirit.
- Recognize that life is a journey, and so is dealing with cancer.

Finding a doctor/getting a second opinion

Finding a good doctor who is willing to investigate and discuss all the options is the most important part of your treatment. In the face of a cancer diagnosis, never hesitate to get second and third opinions, don't feel like you must rush into treatment. Most bladder cancer patients are treated by urologists. Some see oncologists as well, and others track down specialists in the field of urology/oncology. Patients receiving radiation will need a radiologist oncologist, and you may find that approaches differ widely according to a doctor's specialty.

Get your second opinion from a medical professional not affiliated with the first group or institution.

You may want to consider going to a major cancer center or university hospital, where your doctor will have the latest diagnostic tools at his or her disposal. However, major institutes are research oriented, and researchers can be narrowly focused on their field of expertise. Experienced clinicians, if they are the sort of globally curious people who keep up with developments in their field, may have a broader view of the options available.

If cystectomy is indicated, you'll want to find the most experienced surgeon/surgical team possible, preferably affiliated with a major cancer institute. There is a list of cancer centers and institutions that specialize in urology, ranked/listed below.

Choosing a treatment physician and the initial therapy are two of the most critical choices you can make. Here are a number of points to think about:

- Do you want a physician you can trust who will make all the decisions?
- A physician who will explain options but guide you to the choice he believes best?
- A physician who will explain options but be willing to share the choice with you?
- Or a physician who will be your consultant as you do extensive research and choose for yourself?

(taken from Michael Lerner, author of Choices In Healing)

If you haven't already seen this article [Second Opinions: Why, What and Who](#), please read Steve Dunn's advice on CancerGuide, about the importance of, and how best to approach getting a second opinion.

For those who need help finding the right questions to ask, WebCafe has compiled a list of FAQ's for both non-muscle-invasive and muscle-invasive bladder cancer.

Cancer Centers Program of the NCI supports cancer research programs in approximately 60 institutions across the United States through P30 Cancer Center Support Grants. For information about, and listings of these US institutions. <http://www.nci.nih.gov/cancercenters/default.html>

US News and World Reports' top ranked hospitals for urology/cancer updated 2006 At this link you can search for the best cancer centers or urology hospitals in your area of the U.S. f