

# How to be a Proactive Patient

## Part I: A Urologist's Perspective

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Presented by:



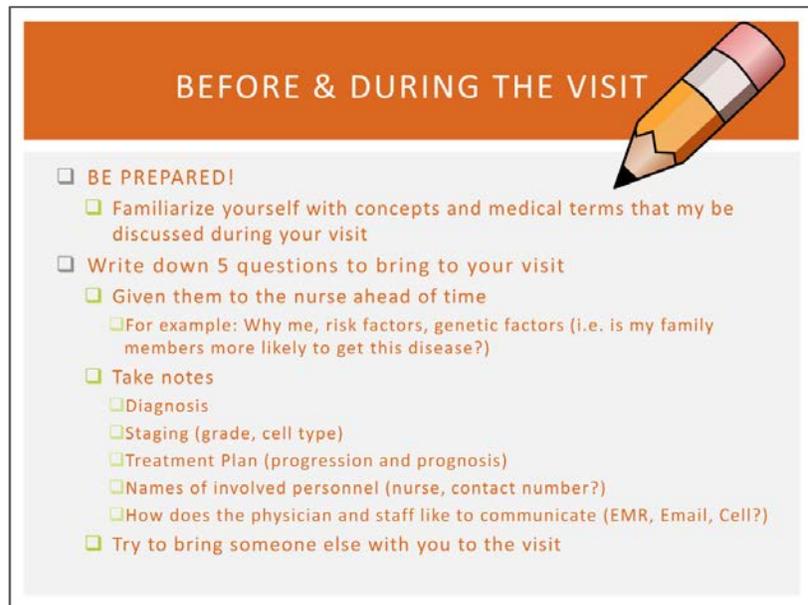
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What I've been tasked to do is just to really look at this from the physician's perspective and the things that I think help patients to get the most out of their appointment, are going to really turnaround the central theme and that is preparation. I'm a firm believer that the more a patient comes in prepared and seeks information and then looks for opportunities after their appointment to gain further information that they're going to become an engaged party along with the physician and certainly at the end of the day we're trying to make patients become informed decision makers.

I think the first and foremost thing is to familiarize yourself with the concepts of medical terms. A great place to start off with that is the BCAN website. Also looking up general concepts on bladder cancer. Not understanding some of the terminology and I always encourage people to write down a couple questions, because listen the visit itself becomes very anxiety provoked for the patient. I think the folks often come in with a lot of uncertainty, a lot of pre-conceived ideas about what is going in, about what is happening to them and sometimes you can lose focus on the agenda of what you're trying to get down. Bring a question that really helps you form your agenda of what you want to accomplish during the visit.

Then you hopefully allow that that palate into collaborative effort with your treating physician. I always encourage to give the nurse ahead of time, I will tell you it's a well-known fact that the nurse is prompt and are their physicians. The staff prompt physicians that happens with me all the time. When you articulate specific concerns or needs to the nurses, often they will be articulated to the physicians and you're just trying again to be proactive and setting up the appointment/visit to get out of it what you need to. Take note, I always encourage people to bring somebody with them.

I think the person with the disease, because it's such a stressful situation and because there's such uncertainty. Especially first that it's really hard to synthesize all the information that's coming to you and I think you have to be realistic upfront about what you can get out of appointment. I will say, you can't learn everything. We can't teach you to be an expert in bladder cancer at one appointment nor at 10 appointments but if you can learn a little bit each time and slowly but surely in terms of that space, then you become more informed and better to make decisions on your behalf and clearly discuss that with your physician.



**BEFORE & DURING THE VISIT**

- BE PREPARED!**
  - Familiarize yourself with concepts and medical terms that may be discussed during your visit
- Write down 5 questions to bring to your visit
  - Given them to the nurse ahead of time
    - For example: Why me, risk factors, genetic factors (i.e. is my family members more likely to get this disease?)
  - Take notes
    - Diagnosis
    - Staging (grade, cell type)
    - Treatment Plan (progression and prognosis)
    - Names of involved personnel (nurse, contact number?)
    - How does the physician and staff like to communicate (EMR, Email, Cell?)
  - Try to bring someone else with you to the visit

Again, bringing somebody to help you synthesize that information and what they heard from an uninvolved, unbiased participant I believe is very important. I think things you want to think about and understand are the staging and figuring out what that means, where you are, is that even applicable to you yet, the treatment plan. When you really discuss treatment plan, things about hey is this going to work? What's the chance that things get worse? What's the outlook for me? I think the other thing that's important for people or patients is to understand the names of the personnel.

If you're seeing a particular urologist, if you know who's the needle for them, who their nurse is, who are their nursing assistants or ELPNs, the names of those people will take you very far in any appointment, because when you call back or when you're looking for answers, if you know names, if you can relate back to them, then there's a much better chance that you're going to get the response/attention that you need. You got to remember often for many people in physician offices, everyone's important but there's a lot of patients and there's a lot to be done each day and you want to start to get a sense of how to navigate the system.

Then I added this final bullet and I didn't have this the last time we did it, but I think this is becoming more important and more relevant. I find it very important for people to understand how the physician staff want to communicate. There's a lot of electronic medical records now that communicate by email, and it's hard-pressed to find systems that don't do this. If that's the way that they communicate and that's the way they prefer to communicate and that's the way that's articulated to you that you will get a response, then that's a good way to follow up, to ask questions and to begin to figure out the way to understand how to communicate with your physician's staff.

Some physicians like to communicate by cell. I have a lot of patients that personally text me. I'm not saying that that's what a lot of people do and I'm now advocating that that's the appropriate way, but it just depends on the dynamic of the physician and the patient and their staff. I think you need to ask these questions and then be clear about how that is so that you can move forward, because it's likely

that if you are a proactive patient, it's likely that you will have questions and again understanding that you can't take all the information down in one setting.

This is an interactive process and that interactive process it refers the patients to slowly but surely understand where they are and where they're going. We'll move on to the next slide. A couple other things, and I think this speaks to the concept of are you in the right place and being a proactive patient and my understanding, that do I feel like the physician is competent in what he's doing and am I getting good and am I getting good and right information. I would just say off the top of the head if they start talking to you about resources and different options of where you go, then you start to get some insight that this is the place that that treating physician has been before.

**TREATMENT OPTIONS**

- Muscle Invasive Bladder Cancer: Cystectomy
  - Do you and your practice perform my type of surgery?
    - What are your outcomes?
    - How does this compare to national standards?
  - Do you perform a laparoscopic or open surgical approach?
    - What are **the differences** in these approaches?
  - Which approach to you recommend for me? Why?
  - What will be the affect on my quality of life?
- Muscle Invasive Bladder Cancer: Bladder Sparing
  - Is this something for me to consider? Why would someone choose this?
    - Radiation +/- chemotherapy
    - Radical TUR alone

Strictly related to if you have to have your bladder taken out. I think it's very fair. I often [truckle 00:11:10] when patients ask me, they often prefix that hey I hate to ask this to you, I'm a little uncomfortable asking this to you about how many of these surgeries do I specifically do and what are my outcomes and how do they relate to national standards. I don't think any physician feels turned off by that, any surgeon feels turned off by that. I think they expect that question. I think you should ask it and I think

what you get back is not just the answer to how they do it but an understanding of how often they do it.

It's just truly something that's in their niche, because most people who spend a lot of time in this space should be able to easily articulate this back and also most places ... who spend a lot of time in this place tend to track their outcomes and know how they compare to nationally or iteratively trying to improve on those outcomes. I think that's a really important question and you should feel comfortable in that space asking that. Just some other questions I asked and this ... That I put on the slide and this really just gets to, hey I've prepped for the visit. If I think I'm going to have my bladder taken out because that's what I believe is going to happen, or this is further down the line.

Things you want again to in prepping and as you learn more, you perform a laparoscopically or open, is there differences in this and then engaging in a more quality of life type discussion and why would someone choose one option versus the other, and what does this mean in terms of quality of life for me. At the end of the day, that's an important consideration. That our hope for all us is that we can treat folks and return them to their environment, but certainly the long term outcomes and the toxicities that they might incur need to be thought of in a longitudinal fashion.

Addressing those early on and understanding not only, hey we're trying to cure the cancer but what else does that mean and engaging a physician in your desires, and what's important to you is really important to your surgeon or physician in terms of making decisions. The other thing that I think's important is that any surgeon should, for people that have muscle invasive bladder cancer that's talking about having the bladder removed, you should understand and they should quickly articulate to you that there are other ways than just removal of the bladder. Doesn't mean it's right for you but not everyone who walks into a urologist's office who is told they need to have the bladder out wants to do that and there are other options and I've listed those down there.

Again, I think that speaks to some world of retrieval and some preparation and some working around consistently and steadily around your disease stage and where you are to help ask those appropriate questions. Then again on muscle invasive if that's what you're there for, the concept of ... There's a lot of permeation, the concept of repeating a bladder scraping or a transurethral resection and certainly engaging a physician and not questioning, opposing that I think is very important. If you are at that level, then I think you should say, "Hey, I'm starting to get a grasp on where I am and the general concepts." Then we use a lot of intravesical, or in the bladder therapies after treatments of bladder cancer that has not yet invaded into the muscle.

**TREATMENT OPTIONS**

- Non-Muscle Invasive Bladder Cancer
  - The role of repeat transurethral resection (TUR): Is this right for me?
  - What is intravesical therapy?
    - What are the different types?
    - Is it right for me?
    - If so, when should it be given and for how long?

Yes  No

Then there's multiple types in those and inquiring about those. How are they given? Where are they given? Is it traveling a distance to see someone? Can this be given in a more local setting because that could be disruptive and then certainly understanding what that schedule looks like and asking for that schedule. Often times in some spaces we get these medicines up to three years, it can be a little bit confusing. Under [inaudible 00:14:52] we give a very detailed schedule so the patient can proactively mark it off for themselves. I think again, understanding where you are, where you want to be and where you're going are important.

Important things to consider and ask. I think other things that start to speak to the concept of hey, is this somewhere that I want to be treated as an institution? How often do you do it? Again as an institution, weigh your outcomes and complications and then getting into the concept of clinical trials. Most places that deal with a lot of bladder cancer certainly understand and participate in clinical trials. Not only ones that they have locally, but also ones that are not local that may be applicable to you and certainly understanding on a more global scale that the BCAN organization's really worked hard for patients to help understand.

Certainly that should be part of the discussion with your physician or at least approaching of is that applicable to you at your current disease stage? Specifically going a little bit more distance cystectomy. I'm a big advocate of this. I think the concept of bladder removal and then how you're going to get your

urine out after is a very, very dead subject. I always tell people and then I think it's very important to separate that out. Number one, to decide if you're going to have bladder removal and then regroup after you've made that decision to what are the type of diversions? Meaning what are the type of ways to get your urine out and what is right for you and having a discussion.

**CYSTECTOMY: DIVERSION TYPES**

- Concepts can be overwhelming
  - Consider breaking up discussion on type of diversion and decision for cystectomy into separate visits
- Which type do you normally perform?
  - Numbers: complication rates and successes
- Which is the **best for me?** Why?
  - What personal variables should influence this decision?



I actually find that to tell people the discussion for me and the patient appears to be better when I give them some information about the different types of diversion. Or that they go out and understand the different types of diversions from their own research and then come back and ask questions. It's really hard to put that in perspective when you have no weapons in your bag to understand what that even means or what it is you're even thinking about. I would encourage you, if you don't ... haven't prepared for that and you're just trying to decide about bladder removal that you then engage in a follow up appointment which most people do, and

come back and then have a second visit where you just talk about the topic of diversion.

Again, I just put that last bullet. I will tell you just on that perspective, I think people come in with a lot of pre-conceived notions about the type of diversion they want and they're often rooted not in not inappropriate reasons, but unrealized reasons in terms of what that really means for them. There's a lot of things that we have to help them with understand what one diversion means for them and what are the pros and cons or pluses and minuses of any diversions. I think that needs to be a very focused and collaborative discussion. Then bladder cancer, we believe or I believe I think is a very multi-disciplinary disease as is most cancers these days.

That's just not the collaboration between a surgical and medical oncologist. That's the collaboration between a surgeon and a radiation oncologist, between a surgeon and a psychiatrist, a social worker, somebody who can deal with the anxiety and the mental part of cancer to survivorship, to nurse navigation, to a lot of resources that people need. When I think of multi-disciplinary, I think one of the resources and people on the team to treat the entire spectrum. Certainly medical oncologist and radiation oncologists from a treatment provider are two of the big additional physicians that are often engaged in this disease stage.

Then I think the other thing of second opinion. When people ask me should they get a second opinion, I would say

**OTHER PHYSICIANS/OPTIONS**

- Do you practice in a multidisciplinary setting?
  - Do you have medical oncologists who specialize in my diagnosis?
  - What is the role of radiation oncologists?
  - Should I see one? Who do you recommend?
- Is a second opinion right for me?
  - If so, do you have any recommendations on who/where?



yes. I followed up with this. I get a lot of patients that come to me for a second opinion, and I think any physician would say to you, or would hopefully say to you, "Listen, at the end of the day this is not about me. This is not my treatment decision. I often ... Most every urologist you're going to talk to or urologic oncologist that you talk to does not have their bladder out. They've not had bladder cancer so they're not walking in the same boat as you are, and you need to at the end of the day do what you feel most comfortable, and if you feel uncomfortable you need to spend the time to get the right information to make you comfortable and at least confident to make a decision that you feel is good for you and you're family."

Second opinion I think is never a bad idea. I'm not saying you always need it, but it's never a bad idea. I always tell people who call me up that, "Listen if your gut's telling you, you should get a second opinion, then you probably should." I think I've touched on a little bit about this. I think the other thing is finding patients. BCAN's done a very nice job of this. Connecting people with other patients. They've done a fantastic job. I think this is one of the greatest resources they have. I know we personally keep our own list and I think the nice thing about a local level patient if you can attain it is just what that process means and that system that you're in. What does it look like in that environment? Not an environment that someone else went through.

The slide has an orange header with the word "SUPPORT" in white. Below the header is a checklist with three main items, each preceded by a square checkbox:

- Support groups
  - Do you have one?
- Can you give me contact information for other patients?
  - Especially individuals who have had the same diversion type as me or have a similar cancer stage as me?
- Additional support
  - What do you offer?
    - Social work
    - Psychiatrist/Mental health professional
    - Nutritionist

To the right of the checklist is an image showing several stylized human figures in blue and black holding hands and standing on top of a blue and white globe.

I think seeking that out and asking for that resource is really important because they can really identify with you where you are on all fronts. Then again I touch on the additional support and the services that might be beneficial and things that I would recommend seeking out. Again in that concept of multi-disciplinary extended beyond just treatment providers, but what are the other resources for you as a patient and your family or significant others. These are some of the BCAN education materials on the website. Again, it's just littered with fantastic resources. I spent a lot of time ...

Quick side note. I spent a lot of time putting together a whole information pack on bladder cancer.

We had an artist, we did all the [inaudible 00:20:57] and it's ... Compared to what BCAN has, it really is not as good, and it just put so many resources and so much effort in. I think as you just said, "Hey, what do I have to do before I go in and visit?" I think you need to download the ... one easy thing is just to download the pack it information booklet and start reading that or looking through that to prepare you as an excellent way to start. I think that's going to be it for these slides for me. I'm going to turn it over to Mary and then be happy to take any questions at the end. Thank you.

BCAN would like to thank



for their support