

How to be a Proactive Patient

Part II: Medical Oncology

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Presented by:



Mary Dunn is a nurse practitioner at UNC Chapel Hill. She works in the multi-disciplinary role within urology and medical oncology caring for patients with genital urinary malignancies. Her clinical interests include survivorship and then development and implementation of survivorship care plans as well as palliative care. Mary's one of the founding members of the North Carolina triangle chapter of Beacon and serves on the board. She helps to organize our annual walks and other projects throughout the year and she serves in the triangle oncology nursing society and the triangle chapter of the society of urologic nurses and associates. Mary received her bachelor's degree in nursing from the University of Virginia and her masters in science and nursing from Duke University.

Mary: I'm going to go through a couple of areas about being a proactive patient that I think are pretty important. I want to touch on some of the medical oncology aspects. As Stephanie said, I work in a pretty unique role where I get to work in urology and medical oncology. On the medical oncology side of things, that's where we give people medicines for their cancers. Things like chemotherapy and more recently immunotherapy. If you can see on your screen that there are a ton of questions that come along with being a patient and caregiver in this setting about these medications.

MEDICAL ONCOLOGY

- Chemotherapy/immunotherapy
 - Why are you recommending chemotherapy/immunotherapy?
 - What are the names of the chemo/immuno drugs?
 - What are the potential side effects?
 - What are the most common side effects?
 - Are there ways to prevent and/or treat them?
 - Where will I receive treatment?
 - How long does it take?
 - Do I get an IV?
 - What is the schedule?
 - What is a cycle?
 - What are the success rates?
 - Am I eligible for a clinical trial?
 - What happens if...
 - I miss a dose
 - I don't feel well enough to take my treatment?
 - It doesn't work

Why are we doing it? What are their names? How am I going to feel? Etcetera. Hearing that you need chemotherapy or immunotherapy is going to be pretty scary. We know that many patients have known other people whether it's family members or friends who have had chemotherapy and have had bad or unpleasant experiences with these medications, but what I'd like to express is that it's important to keep in mind that all chemo and all immunotherapy is certainly not the same. Chemo or immunotherapy for bladder cancer is not the same as chemo for breast

cancer or colon cancer, etc. It's really important to remember that everyone has their each individual experiences when it comes to how they're going to respond to these medications.

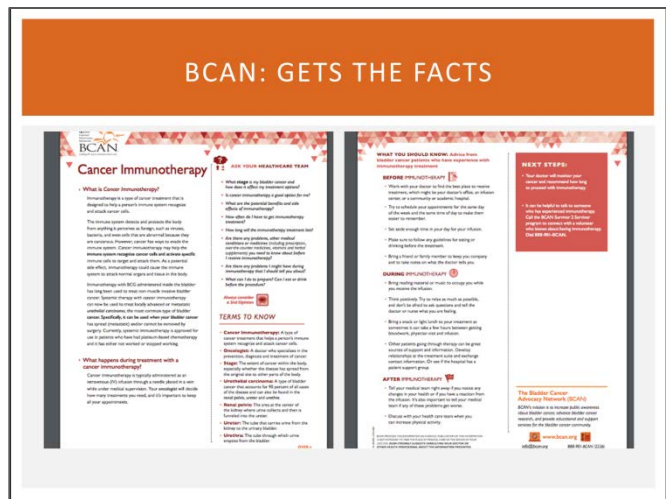
These drugs will be recommended for folks before surgery, after surgery or in a palliative setting depending on the stage of the bladder cancer. One thing that my patients have told me is really helpful is to get a chemotherapy calendar. This can either be done by the clinic nurses or the chemo or infusion

nurses to help keep track of your schedules. Whether or not that's something you plug into your phones or if you're an old spirit like I am and like to hand write everything on paper, that's fine too but something that you can keep track of. Infusion nurses or the nurses who actually give you the chemo immunotherapy are really fantastic resources for educating patients about side effect.

If you forget to ask your medical oncologist or your nurse practitioner about potential side effects, you are going to be with those infusion nurses for hours upon hours at a time and I would encourage you to reach out to them with whether it's drug specific questions or side effects specific questions, they're fantastic resources. Also something to keep in mind is that sometimes with the administration of these medications; there are potential bumps in the road. For example, sometimes we might have to delay the treatment or push it back a week or so. You might have to reduce the dose, you might have to eliminate part of the treatment altogether. This can depend on many things such as how your blood works.

If you're having side effects, whether it's too much to handle that we can't treat alone. We always start treatment with chemotherapy and immunotherapy with this ideal plan, but a lot of times we run into bumps in the road.

To echo Steve about how many resources are on the BCAN website. Again this is not a paid commercial, but their handouts about cancer immunotherapy, about what to expect and also with each of these different fact sheets, there are questions to ask your healthcare team. I think that those are really helpful for folks to maybe print off and take with you for your very first appointment or even subsequent appointments as well.



Managing expectations can be really hard to do in the setting of a really overwhelming time like just receiving a cancer diagnosis. One way to deal with this is to ask questions and ask for clarifications. Not just as that initial consult which can be really overwhelming with a ton of information, but any

MANAGING EXPECTATIONS

- Asking questions and asking for clarification can help manage expectations
 - Not just at the initial consult, but at any visit along the way
- General:
 - Am I still going to be able to _____ during chemo?
 - I had planned to take a trip next month. What if it falls during one of my BCG treatments?
 - My surgery is in 1 month. When will I be able to get back to the gym?
- Examples:
 - Non-muscle invasive
 - Knowing the schedule up front for intravesical therapy and cystoscopy
 - Chemotherapy
 - Side effects
 - Muscle invasive
 - Cystectomy
- Cancer diagnosis and treatment is life changing. Be kind to yourself.

subsequent follow up visits along the way as well. It's really hard to predict how each person will tolerate therapy, and knowing these things in general terms could certainly help ease worry. First, in general things to ask are am I still going to be able to do blank during chemotherapy? A question I get a lot is am I going to still be able to pay golf during chemo? I don't know if that's a North Carolina thing or that's a major thing but I get that question a lot.


Other things are, you know I'd planned to take this trip next month. What if it falls during when I'm supposed to be getting one

of BCG treatments? Should I reschedule the trip or is it okay to defer the BCG? Other things like, my surgery's coming up, when am I going to be able to get back to the gym or back to work, etc. Many times disease says specific things about non-muscle invasive, knowing the schedule, side effects of chemotherapy and the complications for cystectomy. Setting yourself up in advance so that you can manage expectations along the way. Cancer diagnosis and treatment is life changing. Be kind to yourself and know that there might be some bumps in the road. You might not follow the exact pattern that we're going to lay out for you but we're going to do everything we can to help you along.

AVOID INFORMATION OVERLOAD

- Take notes
 - Maintain a notebook/binder
- Ask for clarification
- Bring a second set of ears
- Take a break
- When reading on the internet, visit reliable sources*
- Clinical Summary

*We will provide a list of resources at the end



Information overload I find is one of the most overwhelming things for patients. Some of these things Steve already touched on as far as taking notes, maintaining a notebook, bringing a buddy with you. Something that I also recommend is taking a break. These visits can be long, they can be with multiple providers, you can have folks coming in and out of your room. If you need a break, we want you to ask for a break. We would rather you step out for a minute or two to catch your breath, get some air versus us dump information on you that you're not built for to be able to absorb.

These visits are filled with a lot of information. One of my patient's assignment is keeping a notebook could be helpful so you can keep notes in it. Copies of your blood work, copies of your CT scan report. Sometimes as your providers we tend to bring you through information without knowing or realizing that you may need clarification so please ask. All of us would much rather take the time to repeat ourselves or explain something in a different way than leave you and your loved ones with unanswered questions. A cancer diagnosis as everyone knows is very overwhelming in it of itself. Going to a cancer center, meeting a bunch of new people, receiving all of this information is hard.

Which is why I mentioned taking a break, getting some water. A little side note about information overload from the internet. One thing I'd like to stress is that the internet is full of really, really wonderful resources. Unfortunately, there's also some unreliable and scary and downright untrue information out there. It's important to know that everyone's experience is different. If you read it on the internet, don't assume that it's true or the norm. Just set an appointment with your healthcare team. I have folks bring stuff from the internet with me all the time, which I'm happy to either validate or say, "No, that's not really accurate."

Something I like to do is provide folks with a clinical summary. This is a concise witness statement about what we did at that visit. It usually has bullet points down there about today is chemo number two, come back in a few weeks for chemo number three. Take the magnesium that I prescribed you and here's my phone number if you need me. These visits usually last 30 plus minutes, so providing them bullets of lists of what are the most important things from that visit can be pretty helpful.

We tend to use a bunch of jargon, what I like to call medical lingo. It can be really confusing and a little bit overwhelming. If this is your first time in a healthcare setting or having to encounter something like this, these words get thrown around. It looks like a bowl of alphabet soup sometimes.

This slide is just a brief overview of some of the most common terms that we use when we're talking to patients that have bladder cancer. It's not uncommon that prior to diagnosis you've never heard these types of words. This ties into my first slide about information overload and how to avoid that or at least lower the burden of that. Bringing a buddy and taking notes. Asking us, "Hey, what exactly does that mean?" Sometimes we use terms and you don't know what we're saying it's confusing. For example, something like anesthesia, not everybody knows what that means.

We could then say something like, "That's the medicine that we use to make you go to sleep during your surgery." Or for example CT scan, or MRI. We could say, "That's the X-ray that's used to look inside the body to check to see if there's cancer outside the bladder or etc." If there are words or jargon or terminology that are unclear, please don't hesitate to ask us.

This is a fantastic resource on the BCAN.org website. It's BCAN.org/glossary. They have alphabetically listed the most commonly used terms associated with bladder cancer. It's fantastic. They've spelt things out in lay man terms.

If you're uncomfortable asking for clarification, here's a fantastic resource where you can go to the internet if you have internet access and look it up. It's extraordinarily comprehensive, so just another way that BCAN tries to make things easy for folks, or easier for folk I should say.

Knowing your care team and Steve has touched on this too but I think it's important enough to maybe emphasize it again. There are a lot of disciplines involved in the care of folks that have bladder cancer. Depending on the stage of your cancer, you'll likely have different disciplines as part of your team.

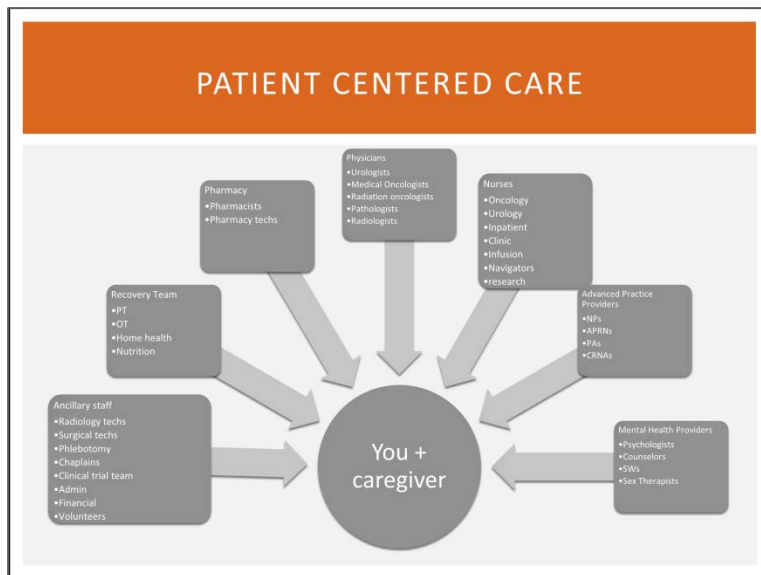
Urologists, different types of physicians, nurse practitioners like myself and physician assistants as well as a variety of disciplines. With so many people being involved in your care, it can certainly be confusing as to whom does what. If you don't have a clear understanding of everyone's role, certainly ask, "What do you do again?" Or, "Are you the person I should contact for this?" Sometimes at big academic medical centers, you might have even more providers than a private practice. In academic medical centers, we have residents so doctors who are training to be urologists or

doctors who are training to be oncologists. They play a very important active role in the care of our patients.

Nurse practitioners like myself are nurses with master's degrees who are educated and trained to diagnose, evaluate and treat folks throughout the life span specifically for me my specialty is [Stanford 00:36:35]. Nurse practitioners are involved in inpatient and outpatient and all over the place. One thing that might seem obvious but a really simple thing is ask for a business card. You'll have everything you need in that one spot. People's names, their titles, their contact information and all of that. A lot of times providers, so your physicians or your advanced practice providers don't always have a direct phone line because a lot of times we're in the clinic all day seeing patients or in the operating room or doing research in the lab.

Different institutions have different ways of managing patient calls and patient communication that Steve alluded to earlier. Sometimes there are three hour lines that are from one main number where folks call and they're vetted through a nursing team. Other folks have nurse navigators. I have phenomenal nurse navigators who work with me at UNC. Some have administrative assistants to filter all the stuff. Some folks communicate via email while others don't. With more and more institutions going towards these electronic medical records, there are patient portals where you can send in your questions. The portals are like an email server but more for secure, and it's tied directly to patient's chart.

If you get these messages, you can look up all your information right there at there at our fingertips. It's also important to know who to call for appointments versus who to call for side effect management versus treatment questions. After hours contact information etcetera.



Patient centered care is something that all of us in the healthcare profession really try and strive for. I always try to include the patients and their primary caregiver or caregivers in the center. Caregivers are so crucial to what we do and how we care for our patients. This is certainly not even an all-inclusive list.

If you look around the circle, either broad categories of folks who may or may not be involved in your cancer team at one point or another, so we all strive do everything we can to make sure you stay at the center of the care that we're providing you. A

lot of people could touch you along the way. It's important to know again who everyone is and why we're referring you to who we're referring to and contact information for all that. The most important takeaway from this slide is that at all times you and your caregivers are at the center of everything that we try to do.

What happens after treatment? We touched on before treatment when you get your initial diagnosis and getting treatment when everything moves realistically. What happens afterwards when things are finished? Follow up schedules. Sometimes patients can feel like they're in limbo once cancer treatment is over. It's a little important to know what the after treatment plan is. How often do you come in for follow up appointments? What will be done at these appointments? For example things like getting blood work or getting X-rays or is it just to see the provider. What's going to be included in these appointments? Who's going to be doing it?

AFTER TREATMENT

- **Follow up schedule**
 - How often do I come in for follow up?
 - What will be done at these appointments?
 - Who will be providing my follow up care?
 - How long do I need to be seen?
 - When am I considered cured?

- **Survivorship Clinics**
 - Care Plans
 - Treatment Summaries



If you had multi-disciplinary care, if you had chemo and radiation, or chemo and surgery, or just surgery, or you're non-muscle invasive and intravesical therapy, so in the bladder therapy and who's going to be in charge? Am I going to be seeing the urologist? Am I going to be seeing the medical oncologist? Am I going to be seeing both? A combination of the two? Am I going to be seeing one of the MPs or PAs? That's important questions to ask. How long is this follow up going to be going on? Is it life time? Is it just a few years? When am I considered cured? After treatment the focus shifts from diagnosis and treatment to this life after treatment.

Long term side effects management, the new norm so to speak and dealing with things like fear of recurrence and uncertainty. Some medical institutions have survivorship clinics which the patient standard clinics are post sickness. No one that's in active therapy. Focus on the things that I just mentioned and also providing things like care plans which outline the follow up schedule and what will be done at those appointments as well as ways to stay healthy, so diet, exercise and things like that. The

TOUGH QUESTIONS/TOPICS

- **Work/disability**
 - Will I be able to work during treatment?
 - How can I file for disability?
- **Financial**
 - Will my insurance cover my treatment?
 - I can't pay for all of this bill. Who can help?
- **Sexuality**
 - How will treatment impact my sexual function?
 - Can I have sex?
 - I am having sexual dysfunction. What are my treatment options?
- **Complementary and Alternative Medicine (CAM)**
 - Can I/should I take vitamins/supplements?
 - What about acupuncture, massage, reiki, etc?
- **End of life**
 - Hospice

treatment summary aspect is that outlines the aspects of the treatment such as who were the providers and what exactly was done during the treatment.

There's some tough questions or topics that sometimes your providers in particular aren't experts in. Are things like work and disabilities, how long am I going to be out of work or am I going to have to be on permanent disabilities, those types of things. Financial aspect of cancer care. Figuring out, is insurance going to cover certain things or if I can't pay for these bills who could help me?

Topics that sometimes for whatever reason are a little bit more sensitive. Questions like sexuality. Asking your provider, how is this treatment going to affect my sexual function if at all. Can I have sex while I'm getting my BCG? Can I have sex while I'm getting chemotherapy?

Then if folks do experience sexual dysfunction how to talk to a provider about treatment options. Other things like complementary and alternative medicines. Can I or should I take vitamins and supplements? What about things like acupuncture or massage? Then something that is hard for not only patients and caregivers, but for your healthcare professionals as well is talking about things like end of life and how to care for a patient who will unfortunately not be cured of their bladder cancer. These are tough things to talk about but very important and we always want you to feel like you can talk to us about things that may be hard.

PEARLS

- **I wish I would have known...**
 - Resources before my visit so I could have written down some questions
 - How big this place is!
 - That parking is a nightmare
 - How long I was going to be at my appointments
 - How hard this was going to be for my spouse. She was my main caregiver and had her own unique needs.
 - Not to be afraid to ask questions. I was raised to never question the doctor.
- **I should have asked...**
 - Can someone stay with me during chemo?
 - Can someone stay with me while I'm in the hospital?
 - What are some things I can do to take good care of myself during treatment?
 - If I don't take treatment, how long will I live?
 - For help from loved ones sooner. It turns out, people around me felt scared, too, and by asking them for small favors like picking up one of my prescriptions, it made them feel like they were helping— and they were!

This section is talking about little bits of pearls of wisdom that Steve and I have garnered over the years from our own patients and their caregivers. I think that's a slide about a few of these and then I'd be interested to hear what other folks wish they would have known. First of all the list here is very brief. We feel all the times that I wish or I could have that had helped me I think become a better provider in providing patients and their care person too, when I know hey I should have said this [inaudible 00:44:24]. The resources before my visit, I hear all the time, "Man, I wish I knew how

good this place was at UNC, but parking is a nightmare. I wish that I could chauffeur every single one of my patients to the front door. Parking was definitely not easy."

People do say, "I wish I knew how long I was going to be here and how long it takes in the lab or how long I have to wait or how long infusion. Something that I did a lot as well I wish I knew how hard this was going to be for ... I had a patient tell me this the other day. She was my main caregiver during my treatment and she had her own unique need. I wish I knew how to help her or how to ask for help for her too. I wish I would have known not to be afraid to ask questions. I have patients who were raised or brought up to never ask question the doctor or never question the nurse, so they just don't ask questions but we really want the folks to do that.

Then just a couple of questions below that are can someone stay with me during chemo or while I'm in the hospital and for help from loved ones. Those are just some pearls that I've collected over the course of my career. It's a very brief side, there could be a lot more. Steve I don't know if you had anything to add to that part.

Dr. Riggs: That was very nice Mary. The other thing I think comes up after having bladder removal, really just any treatment is really preparing for that. Not so much in preparing for the surgery or for a cystectomy. I was talking to two patients about that today in the hospital, but just what is my home

environment going to look like after. That gets a little beyond the scope of this discussion but really just looking forward and maybe making yourself some meals or thinking about how you're going to get to the appointments or what kind of resources you're going to need when you get home and really have that collaborative discussion I think is really important. Things we tend to get so focused in on the moment that we forget about a lot of the things you talked about. That's very nice.

Mary: Thank you Steve. I think the last part that's in there was list of resources. This is certainly not all-inclusive but just some websites for reliable organizations to ... I think all of these websites have not only patient friendly information, but sections for loved ones and caregivers as well which is something that I think is crucial. Of course BCAN number one obviously out of alphabetic order there, but number one of course.

Stephanie: Thank you so much. This has been really a wonderful discussion of some things we think, everybody should know this but as you mentioned there are some patients that clearly are not comfortable asking questions of their doctor because they see them as the experts and they should just do what the doctor says. I think this is a really important concept that we need to be aware of that patients need to, we've always felt at BCAN that patients need to be active participants on their healthcare team and definitely need to speak up when they don't understand something and that's really what we've been doing all along is trying to make sure that we give our best patient education to individuals so that when they do go in and they're signing those forms they truly are giving informed consent, because they know what's happening.

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