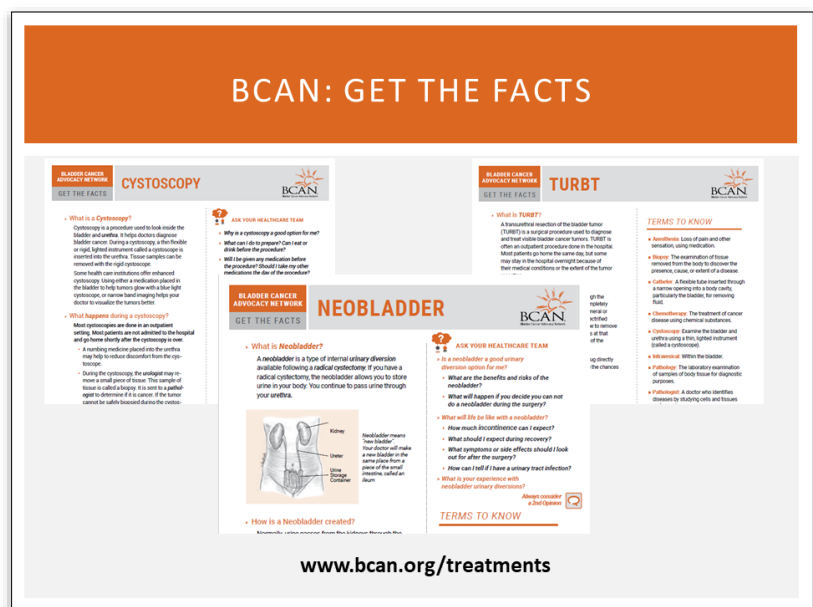


## Stephanie Chisolm:

Thank you so much, Dr. Riggs. That's really great that you highlighted those Get the Facts pages. I think it's important to understand there are actual questions from other patients that are on there that might help guide people when they're trying to think about, I don't even know what I need to know. And so those fact sheets are available on our website in a number of different places. But I think just going and taking a look at that to understand the vocabulary, as you mentioned, so that you really are able to speak to your doctor. They're written in plain language and they're free of charge 24 hours a day whenever you need them. So thank you for bringing those up. Mary?

## Mary Dunn:

Like Stephanie said, I'm a nurse practitioner. I work at UNC in Chapel Hill where it is springtime and pollen time. And I have what I call the best job in the world because I get to work in urology, taking care of patients on the surgery side; and in medical oncology, taking care of patients who are getting medication for their bladder cancer. So I get to do lots of work with lots of patients. I'm going to touch on some of the medical oncology lingo and things that I think are important for people to know, going through treatment if you're getting systemic therapy. So medical oncology is a specialty where the provider, whether it's the physician or the advanced practice provider, are trained to diagnose and treat cancer using medication essentially. So in this context, we think about things like chemotherapy,



[www.bcan.org/treatments](http://www.bcan.org/treatments)

biotherapy; and for other cancers, hormone therapy. And we use immunotherapy, of course, in bladder cancer as well.

So medical oncology can be involved in all stages of bladder cancer. So non-muscle-invasive bladder cancer and also muscle-invasive bladder cancer. And I put some definitions up here just in the event that folks want to have them, which I think you'll have access to this because it's being recorded, but just what these different things are. Right? Because we throw around these terminologies all the time. But a lot of times in the bladder cancer setting, when we're talking about giving people medication, we talk a lot about chemotherapy, which is given through an IV. And we'll go through some of this here. Sorry, my computer is being ridiculous per usual.

### Mary Dunn:

So hearing that you need chemotherapy or immunotherapy or any kind of medication for your cancer can be absolutely terrifying. And a lot of people know others who have had chemo because, unfortunately, everyone knows someone who's had cancer at some point. But a lot of people also know people who have had chemotherapy and have had rough or difficult experiences with it. So what I try and counsel my patients is that it's important to keep in mind that all chemotherapy is not the same. For example, chemotherapy that we use for bladder cancer is not the same that's used for breast cancer or colon cancer or other cancers.

So I think part of being a proactive patient is not only the interactions with your medical care team but also with people in your life, in your support system. Typically, very well-meaning people who sometimes, if they find out you're going through a cancer experience, want to share their stories, which is usually coming from a good place, right? To offer that support. You can be proactive in that setting if you don't feel ready to receive that information from people. If you simply don't want to hear it or it's too scary, it's totally fine to establish boundaries with your loved ones and say, "Thank you for thinking of me and sharing your story. I'm not

## MEDICAL ONCOLOGY

- ☐ Medical oncology is a specialty where providers are trained to diagnose and treat cancer using chemotherapy, biological therapy, hormonal therapy, Immunotherapy, or targeted therapy
- ☐ Medical oncology may be involved in both NMIBC and MIBC
- ☐ Definitions:
  - ☐ Chemotherapy: Treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing
  - ☐ Biotherapy: A type of treatment that uses substances made from living organisms to treat disease
  - ☐ Hormonal therapy: Treatment that adds, blocks, or removes hormones.
  - ☐ Immunotherapy: A type of therapy that uses substances to stimulate or suppress the immune system to help the body treat cancer, infection, and other diseases
  - ☐ Targeted therapy: A type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells

## 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

ready to hear this right now." And I always tell my patients, you can use my name in vain. You can say, "My nurse practitioner told me that it's okay if I don't want to talk about this." So people use my name in vain all the time and I'm completely fine with that.

### **Mary Dunn:**

So this is just a list of questions that I think could be potentially helpful when you're facing potentially getting chemotherapy or immunotherapy or any kind of medication for bladder cancer. So asking the oncology team, why are you recommending this? What are the names of the chemo and immunotherapy drugs? As many of you probably know, the names of these medications are completely ridiculous and everything has two names. I think it's really important to talk about the potential toxicities and side effects which, unfortunately, can be a lot. Thankfully, chemo side effects are usually very predictable as far as the most common ones. And so we can counsel patients really well on those.

The side effects for immunotherapy are not as predictable and most people don't have side effects from immunotherapy. So it's a little bit more of a challenging conversation.

### **Mary Dunn:**

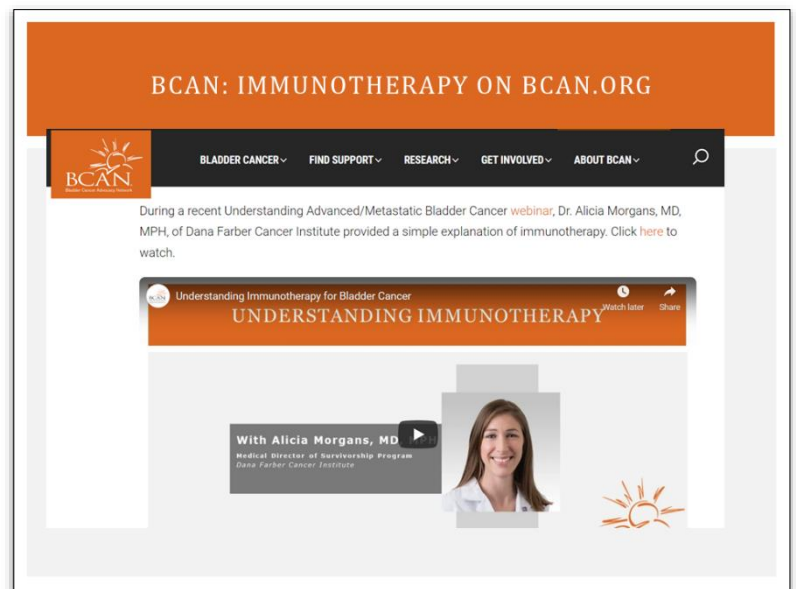
Depending on the stage of your bladder cancer, chemo might be recommended before surgery if you're going to have a cystectomy. It might be recommended in conjunction with radiation therapy if that's the route you go. It might be recommended after surgery if you have a cystectomy. And it might be recommended in the context of a palliative setting with more advanced disease. So all kinds of different scenarios where we could be using these medications. It's also important to ask your team, how long am I going to be receiving this treatment? So how many cycles? "Cycles" is lingo that we throw around a lot. That just means what is the block of time for the chemo? What days am I going to get it on? How long am I going to be up in the infusion center? Am I going to need some sort of IV put in my arm or do I need an IV put in my chest? What are the success rates with this chemo and why are you recommending it? What happens if I decide not to take chemo?

And Steve touched on eligibility for clinical trials is always important to think about too. And then the what-ifs. What happens if I miss a dose? Or what happens if I don't feel well enough to take my treatment? What happens if this medication doesn't work? I think a highly underutilized resource is the nurses who work in the infusion centers are a wealth of knowledge, especially when it comes to side effect management and also setting expectations for what to expect when you get home and how to take your pre-nausea medicine, your post-nausea medicine, all kinds of stuff. So the infusion nurses are a wealth of knowledge there. You might run into a scenario that requires a treatment delay. For example, I had a patient come in last week whose blood levels weren't safe enough to do her chemo so we had to push it back a week. So I think our job up front as providers is to set folks up to know that that might happen, what impact that might have on the big clinical picture.

We're kind of always, in anything we do in oncology, walking this fine line between making sure we're doing everything we can to treat the cancer and also making sure we're doing everything we can to keep you safe. And that can be a fine line there. So if we're not explaining that very well and if we're just coming in the room and saying you can't get your treatment today because your kidney function number is too high, and no other explanation, it's okay to stop and ask for clarification.

## Mary Dunn:

So there's lots of resources on the BCAN website about immunotherapy. I know that immunotherapy has been such a hot topic in the bladder cancer community over the past few years, given how new and exciting it is in this space. I think there's another webinar here by Dr. Morgans, who is fantastic, and there are some information sheets as well. Okay. So touching on managing expectations. And Steve and I are going to overlap on some of this information a little bit. But asking questions and asking for clarification can really help manage expectations. So not just at that initial consult, which can be incredibly overwhelming, but at any visit along the way, whether it's your subsequent visit or post-op visit, or a post-treatment survivorship three years later. Asking questions is what we want for folks to be doing, and quite frankly, what we expect for folks to be doing so that we can make sure we're using shared decision-making and we're all on the same page about what the plan is. It's really hard to predict how each person is going to tolerate each therapy, so whether that's chemotherapy or immunotherapy. But knowing these things, in general, might help ease some of the worries. So for example, what are the most common side effects? When could I expect to feel this side effect? And what are some things that I could maybe be doing at home to prevent this particular side effect?



## Mary Dunn:

The most common side effect with any cancer treatment is going to be fatigue, regardless of stage and/or treatment. Knowing this up front can help ease some of that worry too, and we can help you manage that. So just general questions. Am I still going to be able to do X during chemo? So am I still going to be able to ride my bike 10 miles a day? I had planned a trip next month. What if that falls during one of my BCG treatments? Does that put me at risk for not treating my cancer the way that it needs to be treated? My surgery is in a month. When am I going to be able to go back to the gym or go back to work? And I just included some examples. So for non-

muscle-invasive bladder cancer, managing expectations. Those of you who that's part of your story, knowing that schedule up front, you all know how intense that is, right? So if you're getting BCG, what that schedule is like. And then that follow-up schedule for those surveillance cystoscopies, knowing that that is years and a lot of procedures I think can help manage expectations so that you're not surprised when we say we'll see you again in three months for another scope. Again, talking about side effects with any kind of chemo or immunotherapy. And then as Steve touched on, managing expectations related to cystectomy.

### 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.

## Mary Dunn:

Cancer diagnosis and treatment is life-changing, so I always try and tell my patients, especially in that initial phase because it is incredibly overwhelming. And sometimes it can take a few visits to really absorb what you're being told and what's happening to you is to be kind to yourself and remember to give yourself grace through all of this, because there is no manual for how to really deal with this. And that's why we're here to help you. Avoiding information overload probably seems like an absolutely ridiculous thing for me to be telling you in the context of a cancer diagnosis because I know a lot of us, when we are faced with

something as traumatic as a cancer diagnosis, many people either want all of the information or want none of the information. And then there are some people who are kind of in a middle path.

So visits with your medical team are usually filled with a ton of information. That initial consult visit when the plan is being made can be especially overwhelming, so taking notes to help refresh your memory once you get home. A lot of patients find that keeping a cancer notebook is helpful. You can keep notes, copies of your blood work, and scan reports. So you can also have that as part of your electronic medical record if you connected that with your

institution. Sometimes your providers unintentionally breeze through information without realizing that you might need clarification, so please ask. We would much rather take the time to repeat ourselves or explain something again than you leave with unanswered questions.

And again, Steve touched on this a couple of times, and I'm just going to reiterate it. I cannot stress how important it is to bring someone with you to your appointments if you're able. I do realize there are folks who don't have a close-by support network. It's not uncommon for you to miss something. And having that second set of ears can be a huge help. And also recording, like Steve said. A cancer diagnosis is overwhelming in and of itself. Going to a cancer center, meeting a bunch of new people along the way, and receiving this information about treatment is difficult. So if you find yourself becoming over overwhelmed, it is okay to take a break. Get some water, maybe step out of the clinic and get some fresh air. And potentially even see if you can break that consult visit into two separate visits if you're finding yourself getting overwhelmed. I gave a whole talk on what to not look at on the internet, but for the sake of time, I'm just going to get on my soapbox here for just a second. The internet is full of great resources. Unfortunately, there's also some horrific and unreliable information out there too. And sometimes it's really hard to know what is reliable and what is not.

### 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





## Mary Dunn:

It's really important to understand that everyone's experience is different. I highly recommend online support groups and forums. But always keeping in the back of your mind, just because one person experiences X does not mean that that same thing is going to happen to you. If you read it on the internet, don't assume it's true unless it's coming from bcan.org. And discuss any concerns with your healthcare team. So we have these clinical summaries. So those of you who go to centers where they use Epic, we can give folks after-visit summaries. And what I typically do is just type up a bulletin list of all the important things that I talked about, print it off, and give it so that there's some written information about what we talked about that day. We use so many words that I think we assume that people know, right? Some people have no idea what any of these things mean, and why would you if this has never been part of your story before? We shouldn't expect our patients to be experts, right?

## Mary Dunn:

I would be shocked if people know what a cystoscopy was before coming into the office, so that's why I say... I've counseled a patient today. He needs a cystoscopy. Bladder scope, what does it look like? What does it do? Why are we doing it? It's not uncommon that you've never heard any of these words prior to your diagnosis. So this kind of ties into one of my previous slides about information overload and taking notes and asking for clarification, because sometimes we just assume people know what these words mean.

Sometimes I assume people know what an ostomy is when they're looking at me like I'm completely bananas, which they should because I shouldn't be making those assumptions. And usually, it's unintentional. We don't mean to confuse people. So we could use language such as, if you have to meet with the anesthesia doctor, that's the doctor who uses the medicine to make you go to sleep before your surgery. So just breaking it down a little bit. Thankfully, there is a glossary of terms on bcan.org that has a great resource of things that you can go to and look at anytime. That's the website there. It's really important to know who your care team is. So depending on the stage of your cancer, you'll likely have different disciplines as part of your care team. So that could be physicians, so urologists, radiation oncologists, medical oncologists, nurse practitioners like me, physician assistants are commonly part of your care team, as well as a variety of other disciplines. So with so many people involved in your care, it can be confusing as to who does what.

### MEDICAL LINGO



**HUH?!**

Surgery \* Chemotherapy \* Anesthesia  
Catheter \* Bladder \* Genetics \* Labs  
CT scan \* MRI \* Ultrasound \* PET scan  
Immunotherapy \* CANCER \* Ostomy  
Remission \* Radiation \* Cytology \*  
Infusion \* Metastatic \* Transfusion  
Pathology \* Cystoscopy \* Outpatient  
Neobladder \* Survivorship \* Cystectomy  
Hospice. \* Inpatient

If you don't have a clear understanding of everyone's role, it's definitely important to ask for clarification, especially if you're seeing urology to talk about surgery and medical oncology to talk about chemo and radiation, talk about radiation. Who is going to own which part of your care, not only at the initial phase but after you're finished with treatment? Who's going to be doing those post-treatment surveillance visits is always a big question to know. So at academic medical centers, there may be more providers involved than in private practice. And residents are heavily involved in your care at academic medical centers. And residents are

physicians who are training in their specialties. So you'll see a lot of residents. Nurse practitioners like me are nurses who have master's degrees and educated and trained to diagnose, evaluate, and treat. So I'm an adult nurse practitioner, no kids, no thank you, with a sub-specialty in oncology. And physician assistants have similar training as well.

### Mary Dunn:


Get business cards. I know that business cards seem to be a thing of the past because everything seems to be electronic. But business cards, I think, in medicine, are still really important. So you've got names and phone numbers and all that kind of stuff. Many providers, just to set up expectations here, don't have direct phone numbers. So I get asked a lot for my phone number. I don't have a phone number. I have a cellphone number, but that's a personal number. Because we're always in-clinic, seeing patients, or in the operating room, so we don't have direct numbers. So we rely on other members of the team to help us triage phone calls. A lot of times, the nurses can manage those calls without getting us involved. And if they can't, then they forward it to us and we help out on the back end.

So different institutions have different ways of managing that. Sometimes you'll call in and you'll talk to an administrative support system. Sometimes it'll be a triage nurse. Sometimes it'll be the nurse directly in the clinic. But just knowing who do I call in X, Y, or Z scenario. Another little pearl is making sure you have an after-hours number that you can call in the event that you're having something urgent going on that you need to get in touch with your team about is always a good number to have. Some providers communicate via regular email and some do not. That's a very personal preference. There's lots of ways to get in touch with us, and I think it's important to know which way your team prefers. So what's the most effective and the most efficient? Who prefers what? Emails get lost, I'm sure, as Steve can chime in. We get a million emails a day. I would much rather have patients communicate with me through the portal if you have access to that because it's directly linked to your medical record. So I can just open your message and go right in and see how I can help you. So that just makes it a bit more efficient and also safer from a privacy issue standpoint. And then it's important to know who to call for appointments versus side effect management versus treatment questions. So getting that information up front can be

KNOW YOUR CARE TEAM

- Different disciplines
- Who does what?
- How to reach your team











really helpful and hopefully help alleviate some frustration up front if you feel like you're having to make multiple calls to figure stuff out.

Okay. At the end of the day, what we all do is about you and your caregivers.

Patient-centered care. It's why we do what we do. It's why it's a privilege to do what we do. There are so many people who are going to touch you along your cancer experience, whether it's your primary team with your physicians and nurses and advanced practice providers or folks who work behind the scenes that you don't necessarily see.

So the pharmacy team.

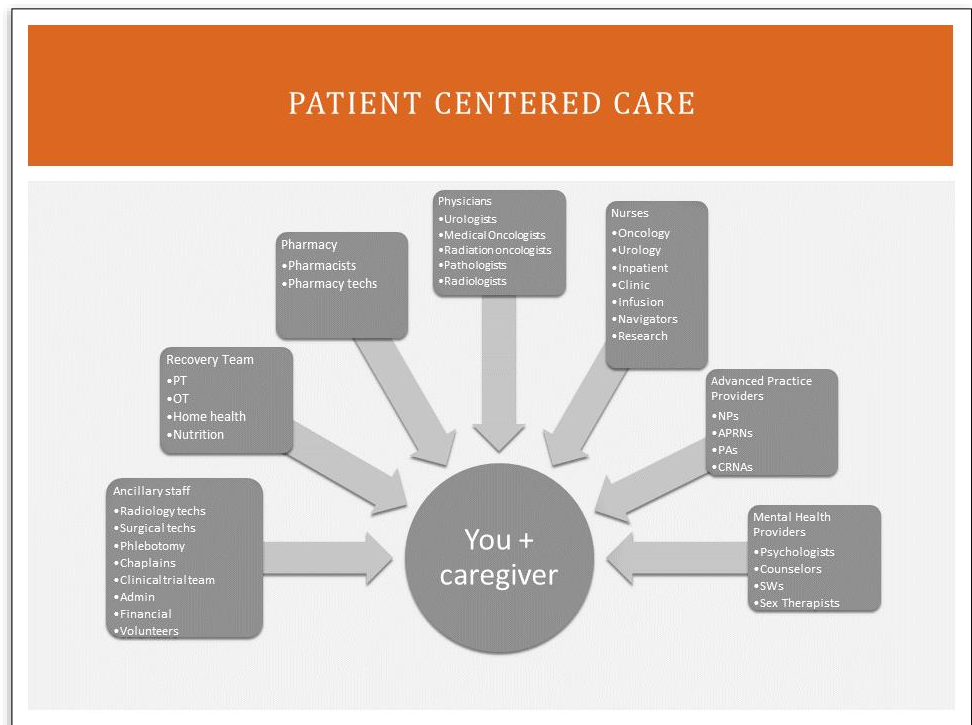
Gosh, what would we do without our pharmacy team? The recovery team, so folks like physical

therapists. The phlebotomists. And this is not even an all-inclusive list, but there are so many people who are involved on your team, which is why it's important to clarify who can I go to for what. And just know, ultimately, we're there to take care of you and it's an honor to do so.

So after treatment, what happens next? So this is always for people who are getting treatment for their bladder cancer with curative intent, and you go into this post-treatment surveillance survivorship phase. That follow-up schedule can be a little bit confusing.

### Mary Dunn:

And you go from seeing your treatment team a lot to, all of a sudden, having months between coming. And that sounds really great at first, but I've had folks say it felt really scary because they're used to coming frequently for chemo, and then you get these months away from us can feel weird. What I tell my patients is that we're not married to that appointment. If there's something going on in-between visits, please reach out. That is why we're here. But it's important to know what the follow-up schedule's going to be like. So when I see folks in the urology clinic, for example, for their post-op cystectomy visit, and then we do a six-week check-in to see how folks are doing, we do these survivorship care plans. So these visits focus from diagnosis and treatment to life after treatment. So managing any lingering side



effects, managing the new normal, which I hate that, but for lack of a better way of putting it. Helping people manage the psychological aspect of cancer care. I could give a whole lecture on that because I think it's so incredibly important. But making sure people are doing well from managing the psychological aspect. Because there can be that fear of recurrence, the uncertainty, all of those things.

But the survivorship care plans are actual paper documents that we give to people that give a summary of what their treatment was, what the follow-up schedule is, some of the expected potential long-term side effects of whatever specific treatment they got, and contact information. And I also send those over to people's primary care providers so that the primary care provider is aware of what we are doing on the cancer side. And then sometimes there are tough questions and topics. So sometimes providers unintentionally don't cover topics that may be really important to you, and reasons for this are plentiful. What could be lack of time, lack of knowledge, level of comfort about a specific topic, et cetera.

And while we might not always have the answer, I certainly don't have all the answers, we can absolutely refer to other members of the team or specialists. So for example, social workers or financial counselors. I don't know how to counsel people about insurance and costs and all that stuff. There are experts on the team who do cancer patient support, nutritionists, sexual health specialists, the palliative care team. And this is just a short list, it's just stuff that patients have told me in the past. I really wish I knew more about these things.

### Mary Dunn:

It's not always that we don't want to, but sometimes we're just not experts. We're not experts in everything. And there's people who surround us every day who can help with these different conversations. So these are just some pearls of wisdom. I'm going to wrap up here so we have time for

## 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

## 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

some questions. But pearls of wisdom, I won't read them all to you, from patients and caregivers. So this is from my personal experience, experience of others, and some stories that I've been told. One thing that people tell me all the time when they come to main campus at UNC, "I really wish I knew how big this place was and how that parking deck is a nightmare." And that might not seem like a big thing, but it is, because it adds like 15 minutes to the visit and you're rushing and all that kind of stuff. People wish they knew how long they were going to be at their appointments. People tell me they wish they knew how hard it was going to be for their

spouse or their partner or their caregiver. Caregivers have their own set of unique needs.

"I wish I should have asked, can someone sit with me during chemo at UNC?" The answer is yes. "Can someone stay with me or sleep in my room while I'm at the hospital?" That's COVID-dependent, of course. And then questions like, "If I choose not to treat my cancer, what does that mean for me? How long will I live?" So these are just some pearls. There are many, many others that we could go through.

And this is a list of vetted quality resources that I recommend perusing in the event you want reliable resources and not just Mary Dunn's blog on the internet. I would highly recommend you stay away from any blog that you see me associated with. I know that was a lot of information, a short amount of time. And I'm, again, so incredibly thankful. I'm going to stop sharing my screen.

### Stephanie Chisolm:

And I do want to just remind everybody that all of these things are possible in almost every situation. And you have to ask and you do have to sometimes stand up for yourself a little bit. And maybe sometimes it helps if you can have somebody else with you in the room so that they can also speak up on your behalf, because I think that's certainly a big challenge.

## 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!

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