Managing Side Effects for Breast Cancer and Ovarian Cancer Through Treatment and Survivorship

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Jessica Jablon:

Welcome everyone. Thank you so much for joining today's webinar, Managing Side Effects for Breast Cancer and Ovarian Cancer Through Treatment and Survivorship with Dr. Seth Cohen and Dr. Jessica Cheng from City of Hope Orange County. I'm Jessica Jablon. I'm the Director of the West Region of Sharsheret. Today's webinar is part of our Sharsheret Summit.

The Sharsheret Summit brings together thousands of people for virtual and in-person education all across the country from September 26th through October 31st. Please visit our Sharsheret Summit website to learn more and to sign up for any of our upcoming webinars that feature top experts in the field.

We have one more webinar coming up, which I'll talk about in a minute, but my colleague is putting the chat for the summit into the chat right now. The link to the chat. We are so grateful for our Sharsheret Summit sponsors, Merck, AstraZeneca, Novartis, Pfizer, Lilly, Daiichi Sankyo, City of Hope, Eisai, and GSK.

Before we begin, a few housekeeping items. Today's webinar is being recorded and will be posted on Sharsheret's website along with a transcript. Participants' faces and names will not be in the recording. If you would like to remain private, you have the option to turn off your video and rename yourself, or you can call into the webinar. We also have closed captioning available. To display live captions on the bottom bar, click on captions and then click on show captions.

You may have noticed that you were muted upon entering the Zoom. Please stay muted during the call. And we will hold a Q&A at the end of the presentation. If you have any questions, please type them in the chat box. We'll get to as many as we can during the Q&A. We also got many, many questions in advance, so we'll do what we can to get through as many as we are able to today.

I want to remind you that Sharsheret is a not for-profit cancer support and education organization and does not provide any medical advice or perform any medical procedures. Our full medical disclaimer is going into the chat right now.

We have one more national webinar left before the Sharsheret Summit comes to a close. Tomorrow, join us at 8:00 PM Eastern, one will be hearing from renowned cancer experts, Dr. Elisa Port of Mount Sinai Health System and Dr. Thomas Buchholz of Scripps Cancer Center, who will be unpacking breast cancer, understanding stages, common types, and rare forms. The link for that webinar is in the chat if you're interested in registering.

But most importantly, if you are currently facing a breast cancer or ovarian cancer diagnosis, please remember that Sharsheret is here for you and your loved ones. Sharsheret provides emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience. All are completely free and confidential. Our contact information is in the chat box now.

Now, before we welcome our experts to the screen, I would like to introduce Deborah who will be sharing her story with us today.

Deborah Binder:

Thank you for having me. My name's Deborah Binder and I live in the Seattle, Washington area. I'm here as a 16-year ovarian cancer survivor. I was diagnosed in 2009 with epithelial high grade serous ovarian cancer and soon after my diagnosis discovered that I was BRCA1 positive.

During my initial chemotherapy treatment, I did have many side effects, which I'm sure you have been experiencing if you're in treatment. And they included fatigue, neuropathy, and brain fog.

And really, how I dealt with my side effects is by really advocating for myself and bringing them to the attention of my gynecological oncologist. And she helped me manage them through really mindfulness practices to help with the brain fog and fatigue and taking care of my physical wellbeing through exercise and good nutrition.

I think one of the things that comes up for me as a 16-year survivor is that I think it's really important to advocate for yourself every single day, not just during treatment. One of the things that happens because of our treatment is that we have lifelong issues, not only because of the treatment, but also as we age. And just a month ago, I had two back-to-back bowel obstructions from the scar tissue in my abdomen that was created during my initial surgery. And so just came out of the blue, but it's something that really has to be attended to. And I ended up having to have surgery to release the scar tissue that was throughout my abdomen.

Luckily, I'm doing really well. The other thing that I am a big proponent of is yoga, mindfulness practices, staying attuned to how I'm feeling and how I'm eating. And that, again, is our lifelong practices. And then the other one that I do want to mention is because I was diagnosed before I'd really entered full menopause, I ended up with early osteopenia and then osteoporosis. And so that's something that you need to think about as you end treatment if you're younger.

So anyway, I'm grateful for the doctors here today to help share what you all can do to help mitigate your side effects. Thank you for having me.

Jessica Jablon:

Thank you, Deborah. There we go. Sharing your story is so important and your message of self-advocacy is so important. And thank you so much for sharing. It really makes people feel less alone when they know that other people are experiencing what they're experiencing as well. So thank you for being here.

Now I'm excited to introduce our first speaker, Dr. Jessica Cheng. Jessica Cheng is among the nation's few and Orange County's only fellowship trained experts in cancer rehabilitation medicine. This is a subspecialty of physical medicine and rehabilitation, also known as physiatry.

From the time of diagnosis, a wide range of physical, cognitive, and emotional challenges may arise throughout the cancer journey. She has the expertise in optimizing function and independence for people with cancer throughout all stages of the journey with a special focus on musculoskeletal and neurological conditions. She is driven to remove function and symptom-related barriers to cancer treatment and to quality of life.

Dr. Cheng partners with each person to help people prepare for cancer treatment and to get back to doing what's important to them. Her goal is to help people live their best life at school, work or home, in the community, or for recreation. And now I will welcome Dr. Cheng.

Dr. Jessica Cheng:

Hello? Can you hear me?

Jessica Jablon:

Yes.

Dr. Jessica Cheng:

Okay. All right. Thank you so much for the introduction and thank you, Deborah, for sharing your story. Thank you, everyone, for joining. I'm so eager to speak on this topic.

First, I will say a disclaimer is that there is much too much I want to say to fit in this time. So I know there's a lot of questions that will remain after this, but I will do my best to answer some of the common questions. So without further ado, let me advance this slide.

So many of you are probably here with this face because you've survived cancer, but are you thriving? So time and again, this is the face I see with my patients and they have a lot of symptoms, many of which Deborah had mentioned that they come to seek my help with. And so these are things that you're probably aware of already.

Surviving cancer, but are we thriving after cancers? The numbers of cancer survivors are increasing. The majority have at least some type of functional limitation. We know that there is more pain, more disability, more chronic symptoms, more psychological symptoms, a lot of things that are worse after cancer, and that a lot of these physical and functional needs remain highly unmet. That's why we're talking.

So the outline is, again, we can't cover all topics like chemo, brain and psychological challenges that Deborah had mentioned, but I want to touch base briefly on fatigue, pain, neuropathy, lymphedema, and I want you to take away the answer of why exercise and why see a PM&R specialized in cancer. So I'm starting with a take-home message so that that cannot be missed. My take-home message is please exercise and please see PM&R physician as early as possible in your journey.

The fatigue. There's fatigue that's cancer-related and there's also fatigue that is not cancer-related. So there are many symptoms that come with cancer and cancer treatment. The reason why I am pointing this out is that a lot of times symptoms are attributed to the cancer, to the chemo, to the radiation, to the treatment, but there are also things that are not cancer or cancer treatment-related that complicate the symptoms, that can cause the symptoms.

So Deborah mentioned that there can be difficulties that come with age. And so oftentimes, it is very complex when we talk about any one symptom. So fatigue, when we talk about cancer-related fatigue specifically, it is a weird type of fatigue where people rest and they don't feel rested. It can occur short-term during chemotherapy, during radiation, and it often surprises people that it lasts long term, several years, even after treatment has been completed.

Many different factors can contribute to cancer-related fatigue. It could be directly from the cancer, directly from the cancer treatment. It could also be because of anemia, low blood count. It could be due to other organs having difficulty like the thyroid, the heart, the liver, the kidneys. Many things can contribute to fatigue. And one of the things that I often see is that people move less when they have fatigue during cancer treatment.

When people move less, they feel like moving less and then they move even less and they have fatigue associated with not moving enough. And so if we are honing in particularly on the cancer-related fatigue, it's a little counterintuitive, but one of the best treatments is actually exercise. It works on the cellular level to help actually create energy for the body, but you have to be careful not exercise too much and get overexertion, not exercise too little and have fatigue related to that. And so exercise, particularly aerobic exercise, is something I emphasize with all my patients that have fatigue.

Now, occupational therapy is a really great partner in terms of energy conservation. They can help with different strategies to pace and prioritize activities to give yourself permission to allow other people to help in certain activities that may not be as priority, but necessary. Treating medical issues is also always important. And what Deborah had touched upon, it is incredibly important. It's always for a lifetime, but especially when there's cancer to eat well, sleep well, feel emotionally well, and also, like I mentioned earlier, move well.

And so here you have the exercise guidelines for people who have cancer, but the catch is this is the same exercise guideline for people with or without cancer, older adults or younger adults.

It's about 30 minutes per day of moderate intensity aerobic exercise, which is to the level that it would not be easy to [inaudible 00:13:13] and whole body strength training at least twice per week.

So I often point out this cancer-related fatigue is one of the symptoms that can benefit from exercise because it is counterintuitive that people don't feel like moving when they're tired. And so I tell my patients, that's exactly when you need to move. When you're thinking, "Oh, I don't want to move." That's when you need to move. And patient after patient has attested that it actually works, that they actually do feel better once they start moving.

Now, moving on to the topic of pain. This is an extremely large topic. So I'm going to fly by and highlight the important parts here. Very common, there is shoulder problems after breast cancer treatment. I actually saw a few of those patients today. You might have heard the term post-mastectomy pain syndrome. This is a very general term for shoulder problems after breast cancer treatment. And most people have some kind of problem and it can be a long-term problem and there can be many different causes.

So the next few slides might be a little bit overwhelming, but it's overwhelming also to say that find a PM&R cancer rehab specialist near you and you don't need to think about these causes so they can think about this for you. So this is a slide on nerve problems that can cause shoulder problems. And so you can see there's a lot of different things here. And there's also a lot of muscle, bone, joint problems that are common in this population.

So what I have underlined are things that are commonly missed. Saw a few of these in clinic today. Myofascial pain with trigger points, kind of like a muscle ... Ooh, something drawn here. Myofascial pain or trigger points, that's like a muscle knot. And commonly what's missed is pain in the pectoralis region, in the chest muscle, and in the shoulder girdle muscles. And so when I see people with pain that's not improving substantially or it hits a plateau with physical therapy, I'm thinking that it might be one of these muscles that has a trigger point that has not been caught or addressed. And another common cause is radiation fibrosis. When there's radiation in that area, it can mess up the nerve and muscle connection and it creates this tightness, spasms, or charley horse, or pain that is characteristic in the chest area muscles. And for that, botulinum toxin is something that is common practice within the PM&R, cancer and rehab medicine field. There's also other aspects like lymphedema that can further contribute to shoulder problems after breast cancer treatment.

Another common topic is aromatase inhibitor-associated musculoskeletal syndrome. This is with hormone therapy. It's very common that there can be diffused joint pain throughout the body or joint pain in a specific location. And this often leads people to stopping the medication, which has obvious implications with the cancer treatment. So in general, interventions for pain, I like to start with prehab because that means there's less to rehab later.

So prehab, what I mean by that is optimizing the mind and body before cancer treatment, before the cancer surgery, as early as possible. And so it has been shown that exercise for the whole body or exercise, say for breast cancer in the shoulder region to optimize that area can help decrease the amount of shoulder problems after cancer treatment. At City of Hope, we do have preoperative rehab education as standard of care. So everyone who's scheduled for breast surgery sees our occupational therapists to discuss the exercises they should be doing in the shoulder region early after surgery to prevent shoulder problems later on.

I work closely with a physical therapist, occupational therapy, and everything you see here. I mentioned some of these before, but as overwhelming as this list can look like, that is what I spend my clinic visits tailoring and customizing to each patient what they need and what they're able to do and what the resources are. So these are oftentimes long sessions with my patients to determine how best to help them recover their shoulder function.

Now moving on to neuropathy. The most commonly discussed is chemotherapy-induced peripheral neuropathy. Now, again, I have to say not everything is blamed on the chemotherapy. I've had patients assume that it was a chemotherapy when they actually had a carpal tunnel syndrome or they had a nerve pinched in their neck. But most commonly, when it is related to the chemotherapy, people get numbness, tingling in their toes and fingertips. And the more chemotherapy they have, the worse it gets.

And it can, with certain chemotherapies common to breast and ovarian cancer, it can get worse for a few months after stopping chemotherapy before it starts to get better. And from the rehab aspect, it's really important to make sure that balance is paid attention to because that numbness sometimes can be insidious. It can creep up on you and we don't like people falling. So if people are doing treadmills regularly, but they don't know that they're getting numb, that could be a fall risk.

So what can treatment look like? A lot of times what ends up happening is that the chemotherapy dose gets reduced or stopped with obvious implications. Cold therapy sometimes can be used to help prevent chemotherapy-induced neuropathy. While there are not standard guidelines on how to treat this, there are a lot of things that can be done. And so exercise is a mainstay. If they have feet neuropathy, balance exercises are important. Collaborating with physical therapy, occupational therapy. Between them, sometimes they can do sports taping, that sometimes it can be helpful for patients. Acupuncture, nerve medications. Qutenza is for when it's painful and nerve medications have not helped. Scrambler therapy is some electrical signals and cannabis is being studied at City of Hope currently. But the take home message here, again, is not to be overwhelmed by the many things that are possible to try, but to link arms with a local PM&R physician who can help figure out what's best for you.

Lymphedema, in a nutshell, this is the lymphatic system. It's like another vessel system. There's lymph nodes and there's lymphatic vessels. You could think of them as train stations and train tracks. If some of the train stations or lymph nodes are removed or damaged through surgery, radiation, or the tumor itself, there can be backup of fluid in the limb. So for breast cancer, it can be in the arm, swelling or breast, chest region swelling. And for ovarian or gynecologic cancer, oftentimes it backs up into the leg or the genitalia. It's important medically to rule out other causes. And usually, this type of swelling is painless.

Lymphedema management, the gold standard is complete decongestive therapy. There's four components. One is compression, which can look like bandaging in the more aggressive phase of management. And then in the more maintenance phase, it'll look like compression garments. There's also manual lymphatic drainage, skincare, and exercise. So all four components need to be present, not just the manual lymphatic massage.

More recently, there are lymphedema pumps that can simulate the manual lymphatic drainage, which is more for the long-term maintenance aspect meant to make lymphedema management a little bit easier.

My key points when it comes to talking to patients about lymphedema is that early treatment is important. Do not ignore it until it gets more swollen, more rigid, and irreversible. Its early treatment is a lot less work overall. A second point is that a lot of ... there's been an ongoing myth for a long time that exercise worsens lymphedema. That is not true. Exercise does not worsen lymphedema. In fact, it's actually recommended. And here, there's a picture of the exercise guidelines again where it shows that exercise can help with lymphedema.

Thirdly, lymphedema is a chronic condition. It can be managed so that it can have minimal impact on functional abilities, but as much as I and many people wish it can just disappear completely, the reality is that it is something that we can manage. At City of Hope, we do have a monthly virtual class where our lymphedema therapists talk about the basics of understanding lymphedema.

Now, I put plastic/lymphedema surgery there as a potential option that we do have available at City of Hope. When the CDT that we talked about earlier, when that's been done and optimized and the patient has been working hard at this and there continues to be some lymphedema, then that is a time when lymphedema surgery referral can be considered.

All right. So one of the things I wanted everyone to take away from this is exercise. Why exercise? You can scan this QR code to dive into more information on why it's important to move through cancer. So the benefits of exercise for cancer patients simplified is that it can help with prevention and survival. It can help people prepare, tolerate, and physically recover from cancer treatments, as Deborah could attest to in her story.

It can improve the effectiveness of cancer treatments. There's more and more research coming out on that. There's a study where people getting chemotherapy before breast cancer treatment, when they exercise, they showed that the tumor was completely gone when they looked at it after surgery in 53% of the patients. And the people who didn't exercise, that was 28%, 53% versus 28%. So exercise has some antitumor effect, and this is a growing area of research.

It can also lower risk of cancer recurrence and improve overall life expectancy. Not to mention all the benefits symptoms-wise here. So the benefits against cancer in the research studies was at this guideline amount. At lower amounts, there can still be benefits in a variety of symptoms.

In the study of exercise versus sedentary, patients who sat a lot, so the black bar is the exercise group. The gray bar is the sitting group. And they exercise people during cancer treatment and the people who sat around more, they did not tolerate cancer treatment well. And this is important because that means these are the people who have their chemotherapy reduced or stopped. So I tell my referring cancer doctors and all my patients, "I want to help you not be in this group. I want you to have your exercise and your cancer treatment benefits." Exercise can reduce pain and heart problems. It can keep people from the ER, decrease hospitalizations, and ultimately, because of these results can cost savings. This is why I harp on this so much.

Now, a lot of people are not so familiar with my specialty, which is called physical medicine and rehab or PM&R. We are not so much organ-specific, but we are the medical specialty of function, and there is a subspecialization called cancer rehab medicine. This QR code links to my professional society. I just came back from a conference there, and that link specifically has a whole list of conditions that you could ask a PM&R physician about, and they should have at least a clue of where to direct you if they cannot take care of it themselves. PM&R is a unique specialty in that it overlaps with so many different other specialties as pictured here.

If you have trouble doing any activity, that's a good time to think about consulting a rehab physician. So if we talk about organ systems, we do focus particularly on the musculoskeletal or muscle, bones, joints system and the nervous system like brain, spinal cord, and the nerves in the arms and legs. So this is particular areas that we focus on, but we also look at the whole picture because function involves so many different components like eating well, sleeping well, and the rest of your organ systems working well and psychosocial systems working well in order for a person to function well.

So one of the questions I commonly get is what should we expect from a PM&R visit? One of the ways to remember this is the 3Ms, movement, motivation, and management. And this is how I, in particular, practice. And so this is a rehab gym that represents our common collaborators of physical therapy, occupational therapy, and speech therapy. There are subspecializations within each of these types of therapists. So it's important to get each of my patients to the right specialist that is fit for them.

My field is highly multidisciplinary, so I'm constantly talking to the rehab team, the medical team, and the cancer team to make the plan work for the patient. Here, we have displayed different tools that can help people with pain, with mobility, with their ability to function day-to-day.

Medications and injections are commonly targeting pain or tightness. It can include nerve blocks, trigger point injections, joint injections, and a number of us in our field also do the Botox injections after breast cancer treatment or head and neck cancer treatment.

The hamburger represents nutrition. Nutrition is important, and swallowing that nutrition is also important. So those are all aspects we keep in mind, particularly for the gynecologic cancer patients. This Squatty Potty here is representing that the pelvic floor function is also important. Dr. Seth Cohen will talk more about that, but there is also pelvic floor physical therapy. In the City of Hope, our occupational therapists also work on sexual functioning through strategies and devices to help with sexual function. And so there are many disciplines that can help with all of these things.

The Tetris is referring to the cognitive function is really important. If someone has chemo brain and they can't remember to go to their occupational therapy appointment for cognitive rehab, then that doesn't work for them. Also, it represents fun because if someone's not having fun, then they may not do any of my suggestions or the exercise that's recommended.

This figure below is that represents that the people around you and the environment like steps to get into your house, those are all important to optimize someone's function. If someone falls, who's going to be there to pick you up, are there trip hazards that can land someone in the hospital. So all this to say, we take a holistic view of the whole person to figure out what will help get them functioning better.

Now, I wanted to talk a little bit more about cancer prehab. This is a growing area within cancer where we try to optimize people physically and mentally before the treatment. And it's starting to show that it can impact cancer outcomes. The key components are exercise, nutrition, and mental, spiritual health. So in my practice, I troubleshoot all the barriers to doing the exercise, nutrition, and mental health. I refer to the specialists as needed, and I have the opportunity to support people's function throughout the cancer journey. So I can see them before the treatment, during the treatment, after the treatment, and continue onwards to address any long-term effects. And a lot of times, giving people the specific program on how to optimize their cancer care really gives them a sense of control.

And so what can PM&R offer? Our goal is to optimize function. So to paraphrase one of the founders of City of Hope, they said, "What does it profit to cure the body if in the process you destroy the soul?" Now, my version is that prehab can potentially profit curing the body. Rehab can restore the soul, and we do this through maximizing function and decreasing disability. And so this graph shows function on the y-axis and a timeline on the x-axis. And the takeaway really is this blue arrow that no matter where someone is in their cancer journey, the field of PM&R and our team is here to help optimize functional ability throughout this trajectory.

And so again, the take-home message is exercise and find a PM&R physician specialized in cancer rehab medicine near you as early as possible. Our team and their team is there waiting for you to optimize your functional ability and your quality of life.

Thank you so much for your time and for spending your time listening to me and hope I can answer at least some of your questions. Thank you.

Jessica Jablon:

Thank you, Dr. Cheng. I did not know so much about PM&R, and I'm sure that many of our viewers learned a whole lot from your presentation. Now, I'd like to introduce Dr. Seth Cohen. Dr. Cohen is a urologist specializing in complex reconstruction of the pelvic floor, including fistula and pelvic organ prolapse repair. Dr. Cohen received his medical doctorate and bachelor of arts degrees at Northwestern University. He completed his postgraduate training in California, including an internship in the Department of Surgery at UC San Francisco, a residency in

urology at University of California, San Diego, and a fellowship in urogynecology and reconstructive pelvic surgery at UCLA.

Dr. Cohen has published in a variety of medical journals on topics including mesh-associated complications, urinary incontinence, and medical education. He is board certified by the American Board of Urology with additional subspecialty certification in urogynecology and reconstructive pelvic surgery. He is very involved in medical education, including being on the faculty for City of Hope's reconstructive urology and genitourinary cancer survivorship fellowship.

Welcome, Dr. Cohen.

Dr. Seth Cohen:

Thank you. Okay, I'm going to share my slides here, so let's make sure that's functional. Okay. Can you ... Let's see here. Do you see my slide deck?

Jessica Jablon:

Yes, you're all good.

Dr. Seth Cohen:

Okay. Well, listen, I really appreciate that very gracious introduction. My name's Seth Cohen. I want to thank Deborah for a really truly meaningful witness and testimony to the power of survivorship of the journey that is. Thank you so much for that. My deep gratitude to Dr. Jessica Cheng for being my wonderful colleague and participant on this panel. I am so fortunate to have her and her specialty and her knowledge at my institution to send my patients to. And obviously, what a truly amazing organization Sharsheret is, and I could not be more grateful to be here with all of you this evening to have the opportunity to talk about ways to optimize your quality of life during your cancer journey.

So we're going to talk this evening about pelvic floor care and optimizing challenges with pelvic floor care. These are really the points we're going to touch on very briefly because we have a very short amount of time. Urinary incontinence and the versions of urinary incontinence people suffer with. Pelvic organ prolapse and vaginal stenosis, two kind of ends of the spectrum of the ways the pelvic floor anatomy can go awry. And then urinary tract infections, which can be extraordinarily bothersome and burdensome for both the patient and really the medical system in general.

The bladder. What do you need to know about the bladder? It's a muscle. That's what the bladder is. It's a hollow muscle. It's got nerves and muscle fibers, and the bladder stores urine and empties urine. That's all of it in a nutshell. So a normal bladder stores urine at low pressures and then empties urine volitionally when you send signals to your central nervous system to contract that bladder muscle.

It's got two sphincters, an internal sphincter and external sphincter. And because as I told you, it's got nerves, neuropathy matters. Neuropathy matters. So systemic therapies, chemotherapies, radiation therapies, surgeries that impact nerves, guess what? They impact the bladder. Diabetes, spinal cord injury, neurological diseases like Parkinson's, guess what? They impact the bladder. So all of this can impact a very important organ of function, and unfortunately, a lot of havoc can occur.

When we talk about urinary incontinence, there's a couple different types of urinary incontinence I want you to be aware of because if you know this terminology, when you go see your physicians, you're going to be ahead of the game in trying to describe to them what you're

suffering with. Urinary urgency, frequency, urgency incontinence. I feel like I'm running to the bathroom all the time. I feel like I can't get to the bathroom and I'm leaking on myself.

As I'm trying to go to the bathroom with the urge, that's a bladder spasm. The bladder muscle is spasming and giving you that sensation you need to run to the bathroom and urine is expelled and comes out at times that you don't want it to. Now, that's a very important particular type of leakage event. Things your physicians are going to want to do is they're going to want to make sure you don't have an infection because sometimes infections can cause bladder spasms, urgency incontinence.

They're probably going to counsel you that if you're drinking coffees or sodas or teas, even teas, believe it or not, herbal teas, those can irritate the bladder at certain times and precipitate some of these symptoms. If you're drinking lots and lots of fluid, which sometimes is really important, especially if you're getting IV hydration in the setting of chemotherapy or systemic therapies, realize your body has to manage that fluid.

So the more fluid you're being given, guess what? The more you're going to have to go to the bathroom. Just be knowledgeable about that. Some people take diuretics to help get fluid off their body. Try not to take those in the evening. Don't take those diuretics right before you go to bed, because guess what? You're going to be getting up all night. There are medications that can relax bladder muscle spasms. I would encourage you to think about those medications as you talk to your medical doctors. They're not on-off switches, but they can lessen those bothersome sensations.

Pelvic floor physical therapy. Just like Dr. Cheng said, pelvic floor physical therapy can be key to making your life better. There are other treatments, and I only say this for you to be aware of these treatments. Bladder Botox. Botox is a paralytic. You can inject Botox into the bladder muscle and partially paralyze the bladder muscle to lessen those horrible urgency sensations. We've done it for many patients that have gone through treatments with radiation therapy for gynecologic ovarian malignancies that have had systemic therapies that cause irritation of the bladder, and they get some sort of respite. They get quality of life back.

Neuromodulation, believe it or not, there's a pacemaker for the bladder. A pacemaker that looks like a half dollar can be surgically placed in the tissues of the gluteus maximus, and it sends signals to the nerves of the pelvic floor to lessen your urgency. And there's even acupuncture, posterior tibial nerve stimulation, which is a little electrode put into the ankle by a nerve that can, again, lessen some of these bothersome symptoms.

Stress incontinence. What is stress incontinence? It's the leakage that occurs when you cough, sneeze, laugh, move. So if you're lifting groceries or if you're lifting a grandchild, or if you're trying to laugh at a movie or cry and you're leaking while that's happening, you're probably experiencing stress incontinence. Pelvic floor physical therapy can be very helpful for stress incontinence, but it's not just Kegels. Some people come to see me, "Dr. Cohen, I'm doing the Kegels. It's not working." It's not just Kegels. It's fairly complex, actually.

There's really good data to suggest that pelvic floor therapy in the setting of gynecologic malignancies and pelvic floor malignancies can make a difference. Now, it's not robust. It's not oodles and oodles of studies, but there's actual good data to say that by doing pelvic floor physical therapy, you can improve your quality of life. Again, not just Kegels. Lots of different types of pelvic floor physical therapies, exercises to do. It really behooves you to work with a specialist for the pelvic floor physical therapist that can go over these one by one with you and really work as a partner to educate you about them.

There are handouts we can offer and give people. These are some of those handouts with websites, but more importantly, it's great to work with someone. And so I would encourage you to work with your particular center of care and see if there's a pelvic floor physical therapist.

There are even some online avenues like Hinge Health is an online product that could be for pelvic floor physical therapy. There are national organizations that have direction about where you could do pelvic floor physical therapy. And so again, I put this simply as resources for you if you want to screenshot it or come back to at a later date.

Inserts. There are special types of inserts that can be used for stress incontinence. They're like tampon products. They're placed in the vaginal canal and they expand to support the urethra. They buttress and support the urethra. They're called Poise Impressa inserts. They come in a sizing pack. You would have to determine if you're small, medium, or large. After our talk tonight, you can go online on Amazon or Walmart or target.com and order these and have them sent to your home wherever you are. And you can try them. Again, it's like a tampon product, so expect that. And then it pushes up on the urethra. You wear it for a number of hours and you throw it away. It's not an on-off switch, but it may lessen some of that stress incontinence.

Bulking agents. You know there's fillers for wrinkles. There's a filler for the urethra. It's called a bulking agent. And so the bulking agent can be injected into the urethra to thicken the wall of the urethra so there's less leakage. There's less leakage. And that bulking agent is essentially creating more resistance. It's like tightening the washer on a faucet. Tightening the washer on a faucet to lessen leakage.

And then there's also synthetic mid-urethral slings. These are mesh slings. Maybe you've heard about this in the news. Sometimes pejoratively. I will tell you there's a lot of great level 1 data to say these are safe, effective interventions that can make a difference. Safe, effective interventions that can make a difference. And so I'd encourage you to really consider discussing this as a surgical intervention with your specialist.

There's also something called autologous fascial slings. These are tendon slings. We can make a sling out of a tendon from your thigh that is then used to support the urethra so you don't have leakage when you're coughing, sneezing, laughing, moving. So lots of different avenues of therapy that can really truly be game changers for someone suffering with incontinence in the setting of a cancer journey.

Pelvic organ prolapse. What is pelvic organ prolapse? Pelvic organ prolapse essentially is a hernia of the pelvic floor. And so it's a weakness in the pelvic floor tissues and the vaginal tissues that allows the neighboring organs to push the vaginal tissues out. So if you have a hysterectomy, what's left? The intestines, the bladder, the rectum, all of that tissue, the neighboring tissue can push that vaginal wall out. And essentially, as I said, it's a hernia of the pelvic floor and you have a bulge or pressure sensation in the vaginal canal.

It can be quite uncomfortable. It can be life-threatening sometimes because sometimes, rarely, but sometimes what can happen, the bowel can literally perforate through the vaginal wall. The vaginal wall splits open, the bowel comes out, and that's an emergency. Your bowels could suffocate. It could lose oxygen. And so if you're having a bothersome bulge or pressure sensation or pain, I'd encourage you to get an exam and have that assessed. Not only should it be assessed, but you could talk about therapies. And so if you're feeling like you're having to use your hands to push the vaginal tissues in so you can have a bowel movement or devoid or pee, that could be prolapse.

If you're having pain with intimacy with a sense of bulge or pressure, that could be prolapse. If you feel like there's tissue there, it's getting irritated and excoriated and maybe even be chafing and bleeding, that could be vaginal prolapse. There are some non-surgical therapies like a pessary. Pelvic floor physical therapy can help. And then there's also surgeries, many surgeries that can make a difference for this.

Let's talk briefly about vaginal shortening and vaginal stenosis. This absolutely is a horrible complication or adverse outcome that can occur in the setting of pelvic floor malignancy. And so

when someone has radiation or surgery for pelvic floor malignancy, that vaginal anatomy can contract and shrink over time. It's possible it could have even been truncated in the setting of a surgery. So it's just shortened based on the anatomical dissection.

What can you do about that? Well, there are dilators. There's vaginal dilators that you can order and you can use to do vaginal dilation to help compensate and over time increase the diameter and length of the vaginal canal. It's again, something you may want to work with a partner on. This is occupational therapy territory. So Dr. Cheng alluded to this. Occupational therapists are trained in utilizing vaginal dilators and how to do that on a one-on-one basis to educate you. So you can do that at home in the privacy of your home.

But I gave you an example here of some vaginal dilators that can be purchased online. This is a particular company I've used before and my patients have liked this particular brand. I gave you a basic strategy. So start with the smallest non-painful dilator, place it in the canal and it stays there for about 20 to 30 minutes, three times a day. And then after three to four weeks, with that dilator, go up in size in the dilator. And then over time, after 5 or 10 minutes, remove the dilators and try to go up to the next size. And so its serial increases in size over time with defined time intervals.

When it comes to the vaginal tissues, the vaginal tissues are dry and atrophic as someone ages and matures. And unfortunately, that's only exacerbated during the course of cancer treatment. And so often, and we're going to talk about this a little in a moment with urinary tract infections, you don't have a lot of options. Some people can't use vaginal estrogen cream. Vaginal estrogen cream is a great therapy for vaginal atrophy. But if for some reason the oncologist you're working with does not feel that's appropriate for you, you can consider a non-estrogen-based vaginal moisturizer. And there's a number of products out there, Luvena, repHresh, Replens. There's a great product called Via vaginal moisturizer, which my patients have really liked. And then Yes VM.

And a lot of these can be obtained again on Amazon. You can go, again, after the webinar tonight, go on Amazon and order some of these things. You could even try pomegranate oil or coconut oil, but those can be used in concert with vaginal dilation therapy to change the vaginal anatomy to improve your quality of life.

Let's talk about urinary tract infections. Urinary tract infections can be horrible. If you're suffering from repetitive urinary tract infections and you're living in urgent cares or on antibiotics all the time, that can really ... It takes you down a notch. It makes you feel like you're just circling the drain. There are multiple ways to help avoid this, many ways to help avoid this. There are some really great guidelines put forth by some professional societies, the American Neurologic Association. I give this to you as a standard that you could potentially read it. It is free and available even for patient consumption. And certainly, I would hope urologists that you see and urogynecologists that you see are familiar with these guidelines as well.

But essentially, if you're getting treated for urinary tract infections, what I ask my patients to do is to consider a catheterized urine specimen. So if you've gone through a cancer treatment and your tissues are excoriated, perhaps you're tired from your systemic therapies, you don't have great dexterity or a little weak, it's going to be hard for you to catch urine in a cup in a sterile fashion. So if you're given a cup and they say, "Go into the restroom and give us a urine specimen," how hard is it to really reach down and get a clean catch urine specimen? Sometimes it's almost impossible.

And so what I really ask my patients to consider doing is a catheterized urine specimen. And so that's where we take a little catheter and we pass the catheter directly into the bladder and we empty the bladder and send the urine off to the lab. That's the best data possible. That's really the best data possible that we can get for patients to lessen the risk of a urinary tract infection or

lessen the risk of being treated for a spurious urinary tract infection. And also to make sure they're on the right antibiotic for the urinary tract infection when they have it.

Now, in terms of evaluation, I think it's important to consider diagnostics like imaging. Most patients getting cancer therapies have some sort of imaging of their kidneys and of their pelvis and also to look in the bladder with a camera. I think that's something unique to a cancer population. If this was someone coming in that didn't necessarily have a cancer diagnosis, oftentimes, they don't absolutely need imaging or a cystoscopy.

I think if you're a cancer survivorship patient or if you're cancer patient, particularly someone who's gone through a gynecologic malignancy, I'm more akin to make sure we have imaging of your kidneys and of your pelvis. And also we've looked in your bladder with a camera to say there's really nothing unusual going on that we would need to be aware of, perhaps a side effect of some of the therapies you've been on.

I would like to just make sure you're aware, sometimes well-meaning doctors will get urine specimens from you and they're going to call you on the phone when you have no symptoms at all and say, "Hey, Ms. So and So, I'm going to give you some antibiotics because there was some bacteria in your urine." You don't necessarily need those antibiotics. And actually, in many instances, we would call it asymptomatic bacteria, meaning there's perhaps bacteria in your urine, but you're not having any symptoms. And we know from guidelines and data, it's not great to treat in those instances because we end up giving you antibiotics when you don't really need them and we create resistance and we perhaps cause other challenges for you in the setting of the use of the antibiotics.

And we know that many people have bacteria living in their bladder. We know that bladders are not sterile environments. And so having some bacteria in your urine in the absence of symptoms doesn't equate antibiotic treatment. And so just be familiar with the word asymptomatic bacteria and empower yourself to know that you don't always need antibiotics if you're not having symptoms, even if your urine specimen's growing some bacteria in it.

What are the common antibiotics we like for UTIs? It's pretty simple. Three antibiotics are generally the ones we use for most women suffering with urinary tract infections. Nitrofurantoin aka Macrobid, Bactrim aka trimethoprim sulfamethoxazole, and then fosfomycin. Those are really the standard first line therapies of antibiotics for patients suffering with urinary tract infections. I'd encourage you to be familiar with that as well because ... And by the way, you don't need one to two weeks of antibiotics. Most women suffering with UTIs really just need three to five days of antibiotics. So if someone's giving you a prescription for one to two weeks of antibiotics, generally, you're in a hospital with a pyelonephritis. I mean, a really horrible infection.

If it's a UTI, say, "Hey, listen, I'll just take three to five days. Thanks very much." Because remember, the more antibiotics you're on, the more you're killing good bacteria in your body, the more you're creating resistance. You want to be laser focused on how many antibiotics you're getting. There are prophylaxis recommendations in the guidelines. I may not go through all these in detail except to say there is something called methenamine. What is methenamine? Methenamine is really ... It's a little dose of formaldehyde if you want to think about it like that.

But basically, it changes the acidity of the urine so the bacteria don't like living in the urine. And it sounds crazy, but it's been used for years and decades as a prophylactic for urinary tract infections. And it's given twice a day, once in the morning, once in the evening, and it's not an antibiotic. It does not create resistance, but we know we do have reasonably good data to say it does reduce the risk of symptomatic urinary tract infections. Some caveats, you have to have normal renal functions, so you have to have good working kidneys. And also, it has to be functional with your systemic therapies.

So generally, what I'll ask my pharmacy team to do is to check the systemic therapies the patient's on, chemotherapies, immunotherapies, and make sure there's no interaction between the methenamine and those therapies. I would say 99% of the time there is no interaction.

Okay. Let's talk briefly ... Oh, follow-up evaluation. You don't need to retest your urine. That's a common misnomer as well. Someone will get treatment for a UTI, and then they're going to say, "Hey, Doctor, recheck my urine." Don't recheck your urine. If you're not having symptoms, you don't need the urine rechecked. It just leads to more antibiotics and honestly, more anxiety. If you're not having symptoms, you don't need another urine test.

Creams and ointments, and we talked about this briefly earlier. If you're in an environment where your oncologist thinks it's okay for you to get estrogen cream, and often that is possible. It really depends on your particular cancer diagnosis and your particular oncologist. Estrogen cream has superb data to say it reduces the risk of symptomatic urinary tract infections. And that's generally put on a fingertip and applied to the entrance to the vaginal canal two to three times a week. Two to three times a week. And so if your oncologist is okay with that, I'd encourage you to talk to your team about that. That can also reduce dryness and irritation.

Now, if you're not able to get estrogen cream, and again, it's really a shared decision-making process with your oncologist and your pelvic floor specialist. As we talked about earlier, there are options. You do have options and they're non-estrogen-based vaginal moisturizers. Luvena, repHresh, Replens, Via vaginal moisturizer, Yes VM. These are all possible. These are all possible. And particularly, the Via moisturizer and the Yes VM are great products that you can use to help with vaginal atrophy that have no hormones in them whatsoever.

Pomegranate oil, coconut oil, also possible, but I would direct your attention mostly to the Yes VM and Via moisturizer in terms of what I see patients really finding most helpful.

So when you have a UTI, my suggestion is partner with a urogynecologist or specialist in this area. If you feel like it's recurrent, you're getting it all the time. Generally, I have my patients call my office. We'll have them come in to do a catheterized urine specimen. We avoid that clean catch. That's a nursing visit. We will give them some antibiotics while we're growing out the culture and then ultimately, we make sure they're on the right antibiotic.

If you notice you're getting UTIs around intimacy, we do give patients antibiotics to take within 30 minutes of intercourse as a preventative as well. One of our last resorts is a daily antibiotic. We really, really hate doing that, but sometimes you have no other option. And so I will put people on a daily antibiotic if there's just no other way to help them and make them better. But again, I try to avoid that just because of the concerns about resistance and your microbiome.

I'm going to conclude here simply by saying find a urogynecology specialist. So if you're someone suffering with pelvic floor disorders during your cancer journey, there is something called the Voices for Pelvic Floor Disorders website, Voices for PFD. You can Google that. They've got a really nice link or a resource on there where you can find a healthcare professional within your geography that's focused on this particular care.

If nothing else, do that. That's my advice for you. Find someone local or regional that can help you with these really debilitating quality of life challenges that unfortunately are only exacerbated often during the cancer journey. And I wish you the best.

I just want to say again, what a true privilege and honor it is to be a part of this, to work with Sharsheret, to be a colleague of Dr. Cheng. It's my life's dream to improve people quality of life. And you all are my heroes for the strength and courage you display on a daily basis. And if I can in any way meaningfully improve your day-to-day, that's really my reward. Thank you very much.

Jessica Jablon:

Thank you, Dr. Cohen. Thank you both so much. I know we learned so much and there's so many questions that have come in and I know we could have probably 500 hours of you answering all of these questions, and unfortunately, we just don't have the time to have that many questions.

I do just want to say briefly that some of the topics that have been mentioned, such as menopause, lymphedema, brain fog, are topics that we do have full webinars on. And my colleague will put in the chat the link to all of our webinars that you can go through and see if any of those will help get some of the answers to your questions.

And I saw that Dr. Cheng answered some questions in the chat, so thank you for that. I did see a couple of questions about vaginal prolapse. One was, is vaginal prolapse obvious to a doctor during a regular gynecology visit? And then can it be seen on an abdominal MRI?

Dr. Seth Cohen:

Okay, these are great questions. Vaginal prolapse, yes, should be obvious to a traditional gynecologist during a pelvic exam. So it'd be identified during a pelvic exam. That's typically what we call a lithotomy exam where you're looking at the vaginal anatomy. It should be done. Usually, I'll have patients Valsalva or bear down so we get a sense of what that dissension of tissue looks like when you're creating a force within your pelvis to push tissues out, but any gynecologist should be able to at least identify prolapse.

As far as an MRI, absolutely. Not an MRI of the abdomen. It'd really be an MRI of the pelvis because this is a pelvic floor disorder. So we'd expect to see pelvic floor laxity on some sort of imaging of the pelvis, perhaps an MRI of the pelvis. An MRI of the abdomen is going to be a little too high to capture the pelvic anatomy and really see that.

Jessica Jablon:

There was a question that came in that I thought was really an interesting one, which was, do you have recommendations for when you go see a physician and they don't seem to be taking your concerns about side effects? They don't seem to be taking them seriously. What would you recommend in that situation?

Dr. Seth Cohen:

Okay. Well, I know my answer. Dr. Cheng, do you have any input on that one? Doctors not taking the concerns about side effects in a real serious, meaningful way. How does the patient approach that?

Dr. Jessica Cheng:

That is so hard. I often see patients who feel that way. I think advocating, finding a PM&R doctor, there's not that many of us specialized in cancer rehab medicine across the nation. I put a list in the chat box of the ones I know of where people are at, but even if they are not specialized in cancer rehab, I think finding a general PM&R doctor to see you where the various issues can still be helpful.

And so you could ask for a referral. I'll put my professional society directory in the chat as well, but oftentimes oncologists are focused on treating the cancer. And so there is a growing movement on treating survivorship issues and symptoms related to that. So hopefully it will bleed over to your office.

Dr. Seth Cohen:

Dr. Cheng and I, you hit a chord with us because we are champions of this and I would echo everything she just said and say you are your best advocate and you live in a modern age where you should not be suffering from adverse effects with no help and no benefit. I'll tell you, at large cancer centers, NCI-designated comprehensive cancer centers, you have multidisciplinary teams trying to help. And so the oncologists are super overwhelmed with trying to treat your cancer as they should be. That is their focus and absolutely should be. But the ones we work with are so superb about referring to us and to their colleagues when there are symptoms that are occurring. And I hope you could find yourself in an environment where those colleagues exist and that multidisciplinary care exists.

So find an institution or a location, if possible, where there's a team of people, a multidisciplinary team of people that have specialists and physicians that really are focusing on those quality of life impacts that just can be so devastating even if your cancer is being treated well. And so be your own advocate as much as possible.

Jessica Jablon:

I think that's such a true thing. And I saw that Deborah, who spoke at the beginning, is echoing that in the chat and certainly her story said that as well. I think one of the last questions ... the last question that I'll ask for right now, just because we're out of time. Yes, I see in the chat somebody's asking about links with the recording and we will put them in the follow-up email with the recording, as well as we will send out some of this information for you to have probably next week.

The last question I want to ask is about neuropathy, which seems to be a very common question in the questions that we got in advance. Just does neuropathy tend to last for forever is basically the question that we're getting. Is there any hope to reducing chemo-induced neuropathy?

Dr. Jessica Cheng:

Yeah, so several questions in there. Usually, I like to see people early on on the more preventive aspects with the whole host of potential ways to address neuropathy that I had on my slide as early as possible. Now, chemotherapy-induced peripheral neuropathy, assuming that's the right diagnosis oftentimes, most commonly, it gets better for most people to an amount that it doesn't bother people significantly.

I often see patients a couple years out after their chemotherapy after they've had this issue. And so what I often tell people is that nerve recovery in general, it works best within the first year and plateaus between year one to two. But if we haven't tried any of the treatments yet, I would hold my assessment because there can still be potentially some improvement.

But if it's been five years, 10 years and you've seen a plateau, then a lot of times, we're not expecting as much nerve recovery and we are learning to adapt with rehab strategies to make life more functional.

Jessica Jablon:

Thank you. Well, with that, I think we have to wrap up, unfortunately. I just want to thank Dr. Cheng and Dr. Cohen for sharing their expertise with us today. Also, thank you again to Deborah for sharing her story with us. As we begin to wrap up, please take a moment to fill out a brief evaluation survey that is being put into the chat. It really does inform our future programming.

We are so grateful to our Sharsheret Summit sponsors, Merck, AstraZeneca, Novartis, Pfizer, Lilly, Daiichi Sankyo, City of Hope, Eisai, and GSK. Also, a reminder about our final summit webinar, Unpacking Breast Cancer, happening tomorrow. The link for that is going into the chat.

Please remember that Sharsheret is here for you and your loved ones. Sharsheret provides emotional support, mental health counseling, and other programs designed to help you through the cancer experience. All are completely free and confidential.

Our contact information is going into the chat box now. And as we come to a close, we've put the evaluation link in the chat box one more time. Please do fill it out.

I saw that there was a question about a topic for a webinar. We do take suggestions. So if you have any ideas for future webinars that you're interested in, please let us know so that we can look at doing them in the future.

Thank you so much to all of you for joining us today, and we hope to see you at one of our webinars soon.

About Sharsheret

Sharsheret, Hebrew for “chain”, is an international non-profit organization, that improves the lives of Jewish women and families living with, or at increased genetic risk for, breast or ovarian cancer through personalized support and saves lives through educational outreach.

With regional offices in the Midwest, Northeast, Southeast, West, and Israel, Sharsheret serves 275,000 women, families, health care professionals, community leaders, and students. Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, approximately 25% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret works closely with the Centers for Disease Control and Prevention (CDC) and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences

- Embrace™, supporting women living with advanced breast cancer
- Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors
- Busy Box®, for young parents facing breast cancer

- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally-relevant publications for Jewish women and their families and healthcare Professionals

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