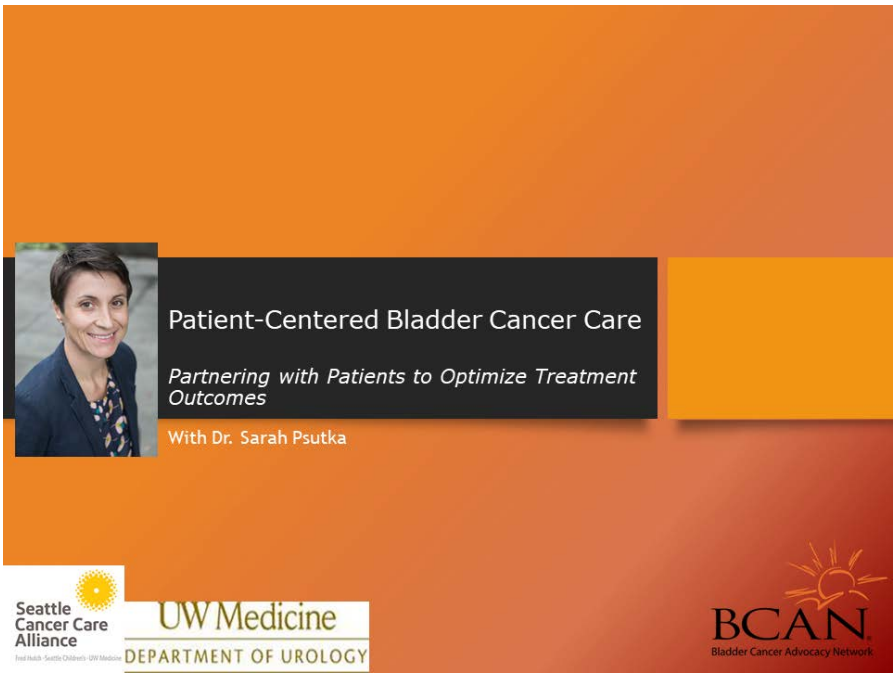
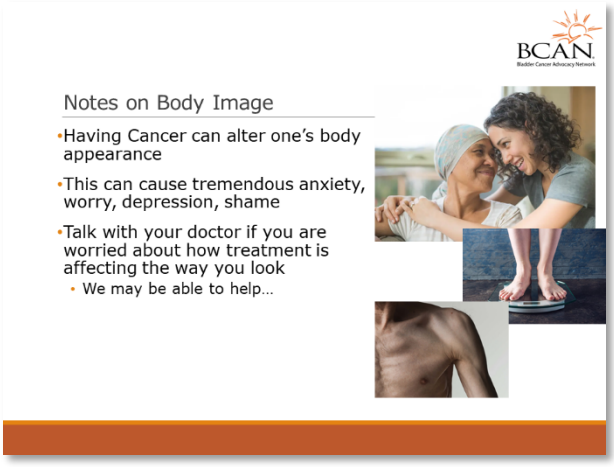


Good Habits for Before and After Treatment



Dr. Psutka: Now, we've been talking a lot about body composition, but I think for bladder cancer patients, another thing that's really important to think about is body image. Having cancer can alter one's body appearance, and this is really important, it's something that I don't think we talk about enough. In terms of how this can affect the way that you look, which in turn affects the way that you feel, I've had bladder cancer patients talk to me about the fact that the weight loss that they can experience, the loss of hair, the feeling that they always look sick, and this isn't of course universally true, but certainly I've got patients who do report this, it causes them to tremendous anxiety, worry, can cause depression, and it certainly can cause self-shame.

I think it's important, if you're worried about how your body is handling these therapies, talk to us because there are things that we can help. The picture on the bottom there is that concept of sort of cancer cachexia, which is this really profound weight loss. If you start noticing that you're unintentionally losing weight, that's actually something that's really critical to bring up with your doctor because that may be a sign of a need for us to intervene in some way, shape, or form to help you with nutrition, hydration, or making

sure that your cancer medications aren't unnecessarily hurting you or making sure that we're fully aware of what's going on with your cancer.

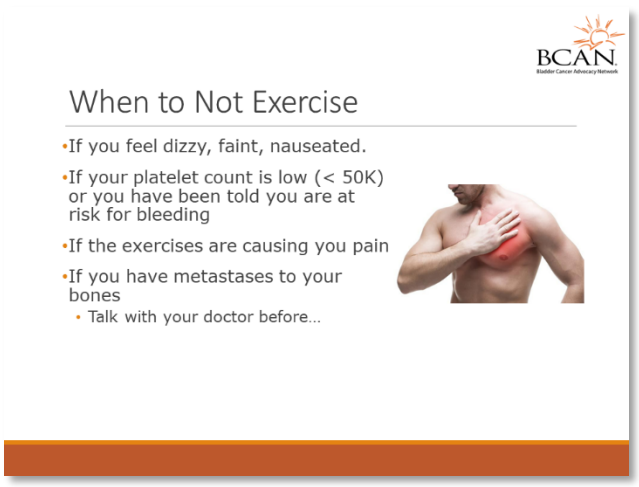
All right let's turn the table and talk about exercise. I think that everybody's heard before the concept of use it or lose it. Exercise is actually a critical thing for you to be doing while you're going through bladder cancer therapy, and this doesn't mean that you have to join a gym, but being active, physically active, is really helpful for patients who are going through bladder cancer therapy. One, it maintains muscle mass, and actually, you can not only prevent further loss, but it may actually help patients gain muscle mass, which think is very helpful. There are lots of studies that have shown that daily weight bearing activity can actually prevent this muscle loss that happens normally with aging, but also can be accelerated in the setting of cancer and can be accelerated in the setting of chemotherapy.

It can also help you maintain your performance status and your ability to be independent and take care of all of your activities of daily living as you're going through therapy, which is important because patients don't want to be dependent on others. It can avoid the dreaded term of frailty, which is something that we worry about and we also are increasingly aware of what a poor prognostic factor frailty means for patients. It can certainly improve how you feel emotionally. We know that when fit folks exercise, they get a real kick of endorphins, and that can be both boosting to one's emotional status, and it can also help build confidence and just build sort of an overall keep your mood up, which is important because this is a long road.

A diagnosis of bladder cancer is a lot to go through for folks. I'm sure that many of the people who have been through the ups and downs and the roller cycle of the constant surveillance and screening with non-muscle invasive bladder cancer, and then with the muscle invasive, going through chemo, going through surgery, going through the recovery, and then going through survivorship. We really want to prepare you and embolden you to get through this as well as we possibly can.

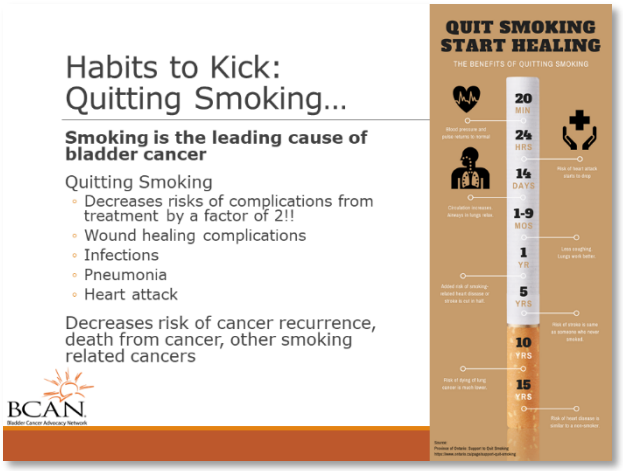
Now, when it comes to how much exercise you should do, you have to listen to your body. Ideally, in a perfect world, it would be great if everyone could, a couple of times a week, get in 30 minutes of exercise. But that's at an intensity that feels comfortable, we're not talking about Olympic lifting or marathon running here. It can be going for a walk, going dancing, lifting weights if that's something that feels good to you, riding a bike, going swimming. I have a lot of patients who do pool walking. But also, yoga, other sorts of plyometrics, anything that really feels good. If you're a hiker and you want to be outside, that's exactly what you should be doing. Strength training is good if it's something that you've done before. If it's new to you, it's something you should start slowly and, ideally, with the help of your physician or a trainer that your physician can help you understand. Endurance sports are important too.

Ultimately, talk to us for ideas. I have always worked with my patients on trying to help them figure out what would feel good. But I think this is something that can really make a big difference in patients' lives.

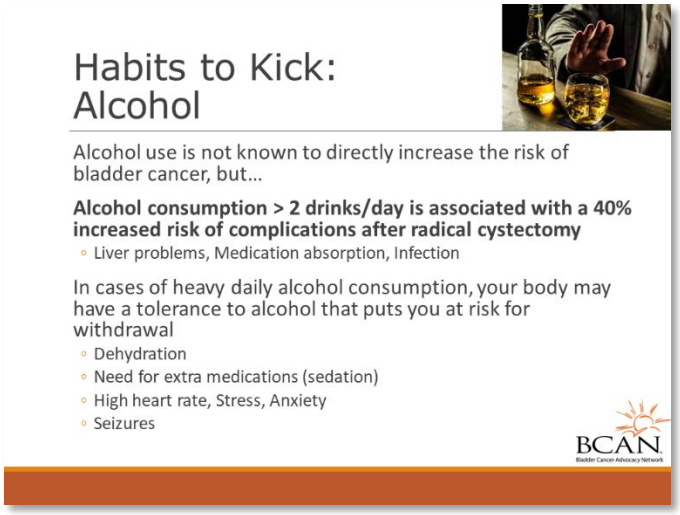


Now, there are times when you're not going to be able to exercise. Certainly, if you're not feeling well, if you feel dizzy or faint or nauseated, this is not the time to try to get in that 30 minute walk. If your platelet count is low, there might be a risk of bleeding, your physician will probably have told you about this, but that's not a good time to be doing anything either because we certainly wouldn't want you to fall and have any kind of major complication. If the exercise is causing you pain, that's absolutely something we need to know about. Then, of course, if you do have metastases that are involving your bones or disease that has spread to your bones, this is something that you should talk about with your physician before you start an exercise program, just to make sure that you're safe. Of course, again, this is where we partner with you and help you figure out what's the best thing for you.

Let's turn now to thinking about bad habits to quit. I think that one of the first things that I ask patients, and I think most urologists who deal with bladder cancer patients, one of the first things we find out from a bladder cancer patient is whether or not they've smoked or especially if they are smoking at the time of diagnosis. Above all else, smoking is the leading cause of bladder cancer. Not only that, it's the leading cause of bladder cancer coming back, and one of the biggest problems with bladder cancer is the fact that it often comes back.



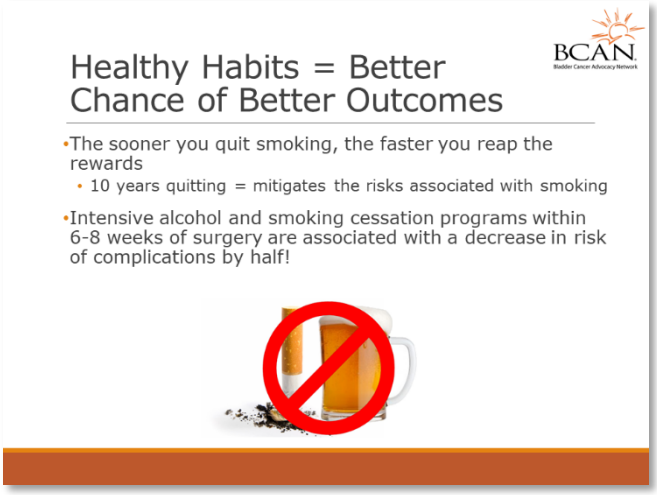
When patients quit smoking, this decreases the risk of complications from their treatment by a factor of two. It halves the risk of all complications after radical cystectomy and after chemotherapy. It decreases the risk of wound healing complications, infections, pneumonia, and heart attack, all of which can result from bladder cancer treatment. As I mentioned before, it also decreases the risk of cancer recurrence, death from cancer, and it decreases the risk of other cancers that can happen because of smoking, like lung cancer.



Another habit to kick is alcohol. Although I do espouse in general a philosophy that everything in moderation is okay, drinking while you're going through bladder cancer therapy, especially if you drink more than one or two drinks a day can decrease your ability to handle the therapies that we're asking you to go through. We know that if you drink more than two drinks a day, that is a 40% increase risk of complications from radical cystectomy. That's largely related to the fact that that kind of alcohol consumption, and two drinks a day may not seem like a lot, but it certainly is a lot for your body to metabolize when we may also be giving you other medicines that your liver has to work through, it can also affect how your medications are absorbed, and it can put you at risk for infections, and if you get infections, that can put you at risk for wound healing complications.

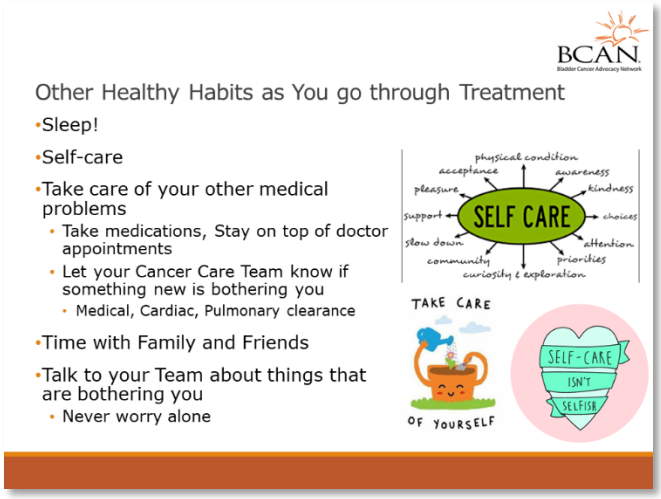
In patients who drink a lot of alcohol routinely, the body can develop a tolerance for alcohol, and that can put patients at risk for withdrawal while they're in the hospital, which can be associated with severe dehydration, need for additional medications to try to handle the symptoms, as well as stress on the heart, anxiety, and potentially seizure risks. Again, this is one of those moments when we start talking to a patient about their diagnosis with bladder cancer and things that they can do to help themselves get

through therapy as successfully as possible. Some things we want you to work towards adding to your life, like good nutrition and exercise, and some things we really want to take this moment to make some really healthy changes in an effort to improve your outcomes and get rid of things like smoking and alcohol that can ultimately make it harder to achieve the sort of outcomes that we're looking for.



We know that the sooner we quit smoking, the faster the rewards are reaped. Within 10 years of quitting, the risks that are associated with smoking are mitigated. So all of those risks I told you about, that twofold increase in complications, the longer you put between you and your last cigarette, the lower those smoking associated risks are. Further, we also know that intensive alcohol and smoking cessation programs within just a couple of weeks of surgery can cut the risk of complications in half.

If you are somebody has a habit of drinking even a little bit of alcohol daily or still smoking, this is a good time to be really open with your doctor. If possible, a lot of our hospitals will offer smoking and alcohol cessation programs that can help you with strategies to really successfully quit.



Other things that can really help as you go through treatments, you need to sleep. Your body needs to rest in order to heal and take good care of yourself at this point, really focusing on self-care. This is a critical moment to do so. Take care of your other medical problems, this is a good time to make sure that you're taking all the medicines you're supposed to take, you stay on top of your doctor's appointments, if you have heart disease, blood pressure problems, or diabetes or anything else, this is a good time to make sure that you're doing everything right to really keep yourself as healthy as possible. If something new starts to bother you, this is a good time to let your cancer team know about it, and especially if you're preparing for something like a radical cystectomy, we're going to want to know about all those things so that we can appropriately have you seen by our colleagues in medicine, cardiology, or pulmonary medicine, so that we can minimize the risk of you having other complications that might be associated with the surgery and the risk might go up if you have these other co-morbidities.

I think it's really important to make sure that you really call in the team and surround yourself with the calvary during this time. Bladder cancer can be a really isolating diagnosis, and I think a lot of patients feel really alone. It's a good time to bring your family and friends to appointments with you, so that you're not sitting through these tough conversations by yourself. It's a good time to really enlist your family and friends to help take care of you, and also to use them as a sounding board as you're working through treatment decision making.

Again, your cancer team is here for you during this, and we really don't want you to worry alone. Also, if we can help in terms of referrals to things like social work, that's something that we can do.

Let's talk a little bit about what surgery looks like. I think that in general, radical cystectomy, as we know, is a pretty major operation. We're going to talk a little bit more about what it entails. But I think that, here at the University of Washington, we have a couple of really exciting things coming down the pipeline where we're working on better understanding, how we can personalize risk stratification before surgery to help patients essentially come into surgery as strong as possible, using targeted interventions that basically identify their own risk factors and try to manipulate them so that you can be as strong as possible when you have to tackle these hurdles of chemotherapy and surgery.

We're looking at things like physiologic age, frailty versus fitness, and risks associated with co-morbid conditions, as well as more interesting and novel ideas, looking at the concept of hope and optimism and resilience, as well as mindful self-compassion to understand how these factors all tie into a patient's success in going through bladder cancer therapy, and also how we can help bolster all of these factors.

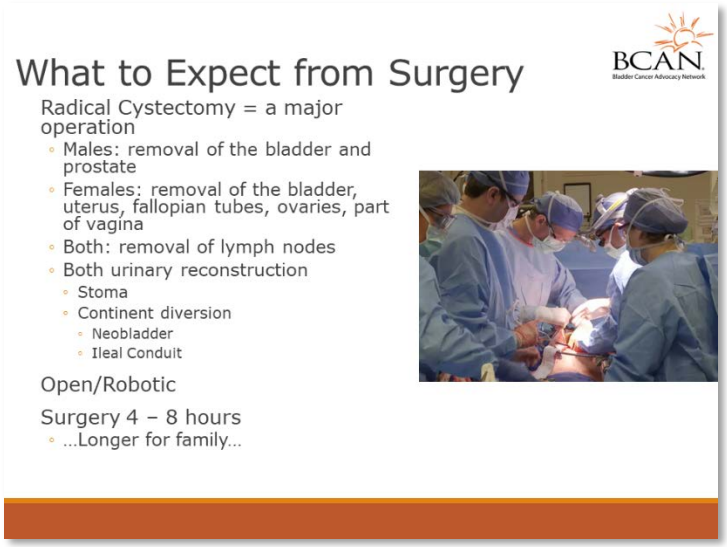
The other important thing to know about is that as you're going through the discussion about the removal of the bladder, there's a lot of other questions that need to be asked. When we talk about risks from surgery, we also talk about the risks that are associated with it that are maybe not directly related to removing the bladder, but what happens when we take the bladder out because of all the things that are near the bladder.

The removal of the bladder in a man involves the removal of the bladder and the prostate. In a woman, it can involve the removal of a lot of the gynecologic organs. This has direct implications for fertility, and if you're still thinking about a family, this is something that you need to bring up with your physician before you go through surgery.

Sexual function is also critical. For men, because we remove the prostate with the bladder, that can impact the nerves that lie behind the prostate that are responsible of erections. Certainly, if sexual activity is really important to you, as it is for many of our patients, talking to your physician about potentially doing a nerve-sparing operation is critical. For women, it's not necessary in every case to remove things like the uterus and the ovaries, and there may certainly be situations where we tailor the operation to a patient, especially if that patient says that sexual activity and preserving sexual function is really important. This is something to make sure that you talk to your physician about.

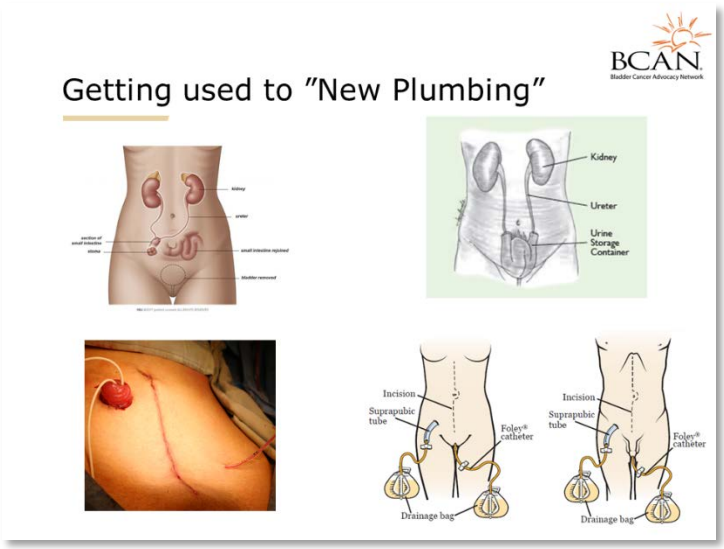
The other thing to talk about, of course, is the urinary diversion. One part, step one of the surgery, is getting the cancer out. Step two is putting everything back together. There are big differences between patients getting a incontinent diversion, like an ileal conduit, which is this picture here, or a continent diversion, like a neobladder, which is this picture here, which is another way of reconfiguring the bowel so you have an internalized urinary reservoir.

But the decision making between these two is actually pretty complex. It's not just as easy as saying, "Oh, I don't want to have a tube or a bag outside of my body." In order to have a neobladder and be a good candidate for it, patients have to understand the potential risks and complications of that, as well as understand whether or not they're truly candidates based on their kidney function, how they have to understand that there's a chance they could have to catheterize afterwards in order to empty urine. Then, also, the implications for what that means because we use about three times the amount of small bowel to make an internal diversion as we do in a conduit. Of course, based on your cancer, you may or may not be a candidate for that. That's something to specifically nail down when you're talking to your physician.



We've talked about the fact that this is a major operation, and it's not just removal of the bladder but in men it also includes the prostate and then in women, it can include the uterus, fallopian tubes, ovaries, and part of the vagina. In both situations, we also recommend a lymph node dissection because that gives us information about whether the cancer is involving the lymph nodes, and we think it also helps us to understand, and it helps us to actually give patients a better shot at long term beating the cancer. Then the urinary reconstruction obviously is critical.

These operations can be performed in several different ways, both through an open incision or, in some cases, a minimally invasive approach, which can be accomplished both laparoscopically or with the assistance of a robotic approach. But this is a big surgery and it's a long surgery. In most places, the surgery can take somewhere between four and eight hours. That's a long day for the patient, but it's also a long day for the family. I think it's important to have those expectations in mind as you're preparing for the operation.



In terms of what the recovery once the patient comes out of the OR, there's a lot to get used to. The first thing is getting used to the new plumbing or basically the new urinary reconstruction. On the bottom here, you can see a picture of a patient who's just gotten out of surgery and has the lower midline incision, the little drain

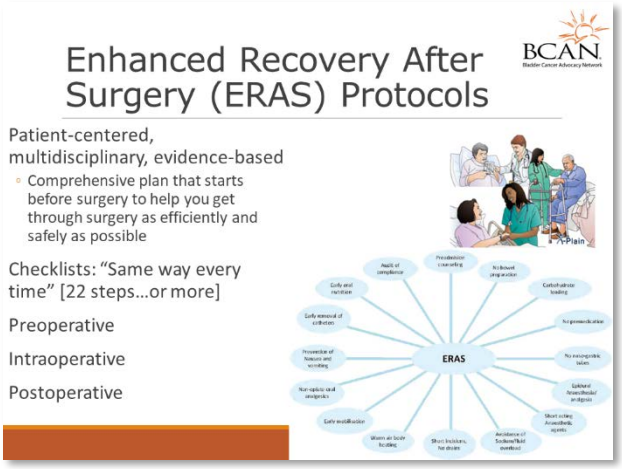
here, and then this is a brand new, freshly reconstructed ileal conduit with the stents that go up into the kidneys. Other patients might come out of the surgery, if they've had a indwelling neobladder constructed, such as this picture here, you might have a couple of other tubes. I think it's helpful to go through before surgery with your surgeon what all of these different tubes and drains are going to look like, just so that there's no surprises when you wake up.

On average these days, patients stay in the hospital about five to seven days, but complications and setbacks after this operation are common. In fact, they're more common than not. One thing I often tell patients is that with this operation, it's very much the case of three steps forward, two steps back. Every day, you get a little bit better, but sometimes, there are going to be little blips. 50% of patients, even at high volume hospitals who are doing a lot of radical cystectomies will have something happen in the recovery that doesn't go quite according to plan, and whether that's need for a different medication, need for a blood transfusion, need for additional imaging, it's common, and it's actually, unfortunately, normal, but it's because this is an operation with so many moving parts and such a complex reconstruction as well.

A lot of patients, up to 25% of patients, will need additional care after surgery in nursing facilities or need some help with home nursing care or home physical therapy. Like I said, the vast majority of patients who come back to us, they come back because they get dehydrated. We'll generally schedule frequent visits once your surgery's over for lab monitoring and to make sure everything's going all right. This is really for your protection, to make sure we know absolutely what's going on and we're doing everything we can to keep you healthy.

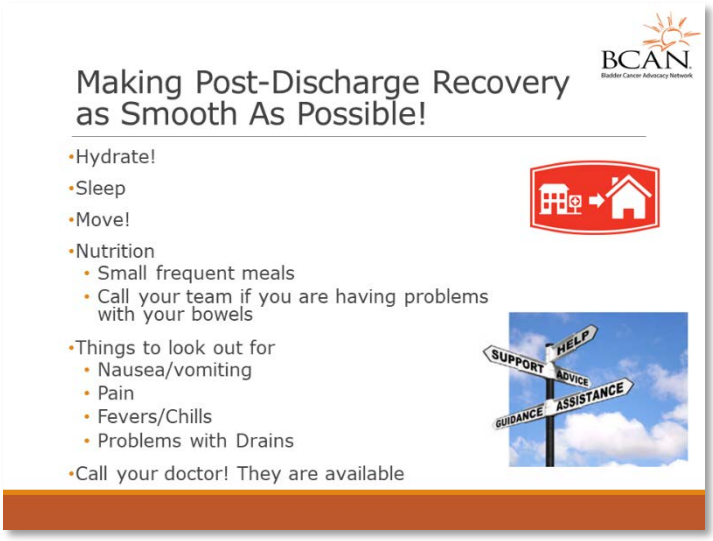
One thing that a lot of high volume bladder centers are now doing is using these enhanced recovery after surgery protocols or ERAS protocols, which are patient-centered multidisciplinary and evidence-based checklists that we follow. Basically the comprehensive plan that starts way before surgery in terms of getting you ready for surgery, carries through the post-operative hospitalization and the actual operation itself, and then your recovery.

There is 22 or more components to a proper ERAS protocol. As I said, it starts all the way from well before you sign the consent form to when you leave the hospital. It



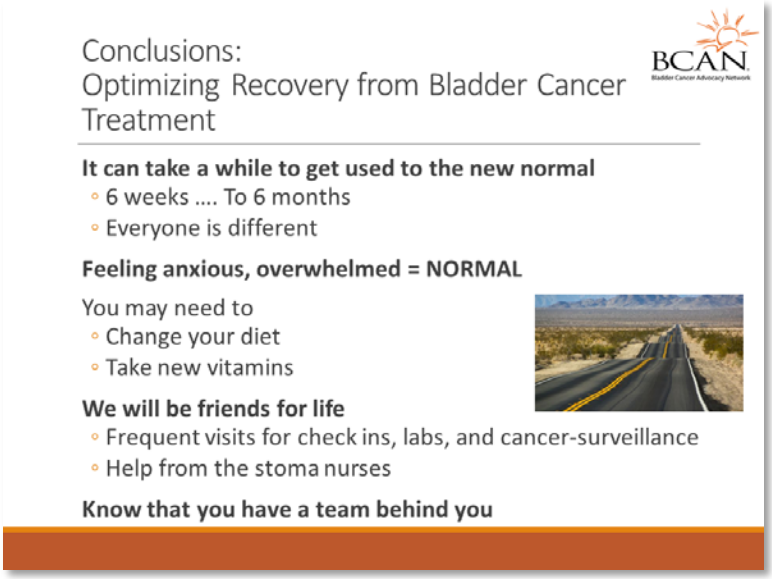
includes everything from specifically making sure that all your questions are answered and you've been appropriately counseled, making sure that we don't do anything we shouldn't do or we don't need to do like give you a bowel preparation that might be dehydrating. We try to have patients make sure that they're well nourished coming into surgery to the point where we ask them to carbo-load before surgery, just like you might have heard marathon runners do. We work really hard to make sure we're giving you medications that are helpful, but not going to hurt you, so we oftentimes minimize narcotics, and so on and so forth, doing everything we can to basically get you back on your feet, feed you early after surgery, get you up and moving early after surgery, and really help you get back to independent living as quickly as we possibly can.

Then, in terms of making your post-discharge recovery smooth, we want you to hydrate, we want you to sleep, we want you to walk, and this is kind of the tough love part of this operation. We know that patients who walk after surgery have a lower risk of pneumonias, their bowels get back working faster, which means they can eat faster, walking decreases the risk of blood cloths. All of these are really important. A lot of times, we'll get patients up and moving the first day after surgery, and we'll make sure your pain's under control, but we're going to ask you to get up and start moving your legs because we know that that helps you get back on your feet ultimately faster and better.



Nutrition, a lot of patients are not going to feel like eating right after this operation, one, because the bowels take some time to wake back up after anesthesia. Additionally, because sometimes food can taste different after you've had this operation, whether it's related to the chemotherapy or whether it's related to the metabolic changes that happen when we have a little piece of bowel now being our urinary reservoir or our urinary conduit. Certainly, I think that a real focus on good nutrition after surgery is critical. We want to know if you're having nausea or vomiting, pain, fevers, chills or problems with any of your drains.

It's really important that you know you should never worry alone after a radical cystectomy. You call your physician right away and let them know if there's any questions so that we can triage problems early and appropriately, get you back to the hospital if we need to, or just help manipulate your medications, that you can be ultimately feeling as well as possible, as fast as possible.



I'm going to end here, and I want to conclude by saying, this is a long road, and it tends to be a pretty bumpy one. It can certainly take a while to get used to the new normal after going through major surgery for bladder cancer treatment, anywhere from six weeks or almost up to six months, and everyone's a little bit different. Going through this process can make people feel anxious and overwhelmed, that's normal. You may need to change your diet, you may need to take new vitamins, but the thing to know here is that you're not going through any of this alone. Although it may feel like you don't have a lot of control, there's actually a lot that you can do that directly impacts your outcome, and I think that that's something that's important for patients to hold onto and to understand they still have a lot of agency in this moment in time.

You and your physician are going to be friends for life. We're going to have frequent visits immediately after surgery for check ins and labs, but long-term, we're still going to be seeing you frequently, especially over those first couple years for cancer surveillance. Then, oftentimes, our hospitals, they're doing these radical cystectomies and have great stoma nurses and other ancillary staff who can really help you, so that if you have specific questions, whether it's for physical therapy, stoma nursing, or nutritionists, make sure that you let your doctor know so that we can get you in touch with the right people right away.

Ultimately, know that you have a team behind you and we are here to help you, and we want to do everything we can to give you the best possible outcome, starting from when we have that first moment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