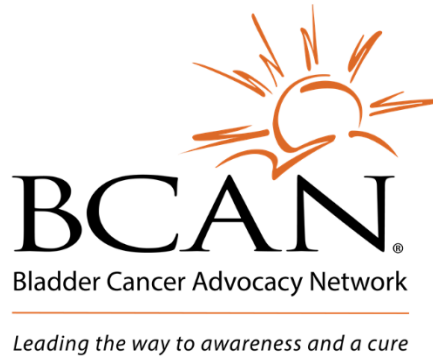


TREATMENT TALKS

What you need to
know about long term
management of
urinary diversions



Question and Answer

Stephanie Chisolm:

There are a couple of good questions that have come in. The first question is, I would change my urostomy pouch every seven days and had no problems with leaks or other similar problems. **Is there any reason not to use a seven day routine as long as the pouches are not causing wearing problems?** Dr. Schuckman, what do you say to that so others would know about that?

Dr. Anne Schuckman:

Yeah. Patients ask all the time about the frequency with which they need to change a pouch. And I think just to set a bar, the average is probably twice a week. I would say most of my patients say, "I just change it on Tuesday and Saturday. That's when my daughter comes over and helps me," or whatever it is. Or, "That's when I do it." I certainly have patients who wear their pouches longer. If you're not having problems, I don't think there's any medical reason why you need to change your pouch more frequently. The main reason people change them at that three to four day interval, is because if they don't it'll start to leak or they're not confident that it won't leak after that time. Personally, I think if it's working for seven days, you're not having skin problems and it's not leaking, it is probably just fine.

Dr. Kamal Pohar:

Yeah, I think definitely if it works for you, then I think it's very acceptable. But in general, one looks at the Wound, Ostomy and Continence Nursing Society, or WOCN recommendation. But the recommendation Dr. Schuckman points out is every three to four days and that's really to prevent against skin breakdown that can occur. So use of adhesives and the wafer starting to saturate urine under the wafer, some of the preservatives start to get eaten away at when the pouch is on too long. I think really, the recommendation, it's really for skin health. But if your skin health is good, and you're not suffering from urinary infections, which is another reason to potentially change your ostomy appliance twice a week. If you're having no downstream effects of keeping it on for a week, I think naturally it's very acceptable. I have many patients who also adhere to the one week policy and not every three to four days. But again, I think it's a very fine balance. It's very specific for a given individual whether it's acceptable to do it this way.

Stephanie Chisolm:

Okay, great. Let me get to another question then because we have quite a few. **Is there any recommendation to avoid urinary tract infections as far as rinsing out a night bag with water or Clorox solution, or even a rinse of the pouch on a regular basis? Or is it best not to bother with those things and there's not a whole lot you can do?** What other kinds of things can patients do for all types of diversions, in terms of diet and fluid intake to reduce their risk of developing urinary tract infections?

Dr. Kamal Pohar:

I think that's such an important topic. I think the starting point is hydration, I think that's very important to really try to minimize the large count of bacteria that exists in the diversion. To dilute it and to reduce the concentration of bacteria. So good hydration's great. Nutritional aspects, certainly it doesn't hurt. The strength of the medical evidence that having specific types of nutrition or a certain diet reduces the risk, I think we'd be hard pressed knowing that. But I think a very healthy diet obviously builds immunity, builds strength, provides good nutrition to the body. These are all things that are helpful for our defense mechanisms. So I think that's a very important point. Cranberry juice is known in many fields of medical practice, whether you have a diversion or not, cranberry does change the concentration of the urine and can reduce the risk of urinary infection. I think these points are important. Changing your appliance in a structured manner on a specific routine, three to four days, is important. If you're getting infections, that nighttime bag, changing your bag once a week, the nighttime bag. I know that's a recommendation of WOCN. And they do recommend cleansing your ostomy bag with the product that was mentioned in the question. That it is a good way to cleanse your bag. I think many of the points were brought out in the question itself and the points you brought up, Stephanie, I think we certainly all endorse them as all techniques to try to reduce your risk of infection.

Dr. Anne Schuckman:

We could probably address a few others that I thought of while you were talking, Dr. Pohar, as well. I'm curious for Linda with the Indiana if you've ever really had problems with recurrent infections. We routinely tell patients they can use the same catheter over and over again if they're catheterizing, whether it's a neobladder or a continent cutaneous diversion. But if that's not working, then another technique is to change to single use catheters that you throw away or more routinely irrigating a neobladder. We don't always ask patients to irrigate long term, but if infections are an issue, we may ask patients to do that.

Linda Waddell:

I haven't had any urinary infection and I reuse the catheter. But when I first initiated that education about what to do, I use a Dial antibacterial soap and I wash the catheter and then I use hot water and then I air dry the catheter in between a towel. That is what I was told to do and I do that pretty religiously. And I always wash my hands before I do the catheterization with the antibacterial soap.

Stephanie Chisolm:

Okay, good. All right, really helpful information. Obviously, when people have bladder cancer, they're going to continue to have a relationship with their providers and there's a good question in here. **I always wonder when I'm asked to give a urine sample, would I give it from a clean bag, but tell them it's from a urostomy?** But I've heard people say it's done differently. Please explain what is best when asked to give a urine sample. Either of you.

Dr. Anne Schuckman:

I can give my two cents on that first. The thing that drives me probably the most crazy as a urologist, is when patients who have ileal conduits come in and they say, "Oh, my gosh. I've been on antibiotics five times since I've seen you last." I say, "Well, have you been sick?" They say, "No, I'm totally fine. My doctor just keeps sending urine cultures and they keep being positive." Many of those cultures get sent just from the bag and to me, to be very graphic, I feel like that's the same as just sending it from the toilet water. That's not a sterile environment. I do not treat infections based on that kind of culture. So for somebody who has a urostomy, if we really need to determine what is going on, I like to catheterize the stoma and drip a culture into a sterile cup. And really do that in a sterile fashion. Most people who aren't urologists aren't going to ever do that. Now, if you're in a situation where you have a fever, or symptoms and you're sick and your doctor needs to put you on some antibiotics and sends a culture in another way, by all means accept the treatment. But otherwise, if you're asymptomatic, I think that trying to collect a cleaner specimen is probably more efficacious so you're not on antibiotics unnecessarily. I'm very passionate about this, so I apologize for being so passionate about this.

Dr. Kamal Pohar:

Another practical point though is another way to possibly get a better sample is if you can change your own appliance in the physician's office. If you have a spare with you or you bring it and you could put a clean pouch on. It's a little time consuming to just wait. That's another way to sometimes help the doctor out too if you're not in a urologist's office. Most doctors' offices are not very adept at changing your appliance or what to do. But certainly you might be able to help that situation.

Stephanie Chisolm:

Very good points on both and I will definitely think of that in the future as far as yes, if you're getting a sample from the bag, it's like taking the sample from the toilet bowl and it's going to have other issues. That was definitely something that will stick in everybody's mind because it's stuck in mine.

I was hospitalized two months after surgery with bacteria in my blood, resulting in a sepsis. Will I be more prone to this in the future? Is this something that you see commonly, or is this something that's more of a rare situation?

Dr. Kamal Pohar:

Well, I think the starting point is it all evolved from the topic we've been having some dialogue about. It's a urinary infection, so unfortunately a urinary infection got so severe it entered the bloodstream. Hopefully, it won't happen again, but I think it's important that that be investigated, are there any underlying influences of the diversion that can be corrected to preventing another severe infection. Are there any stones, is there any obstruction? Some of the points that were on a couple of the slides. I think it's prudent to look into some investigation with fingers crossed, hope they won't happen again. But unfortunately, there's no guarantee. Any urinary infection there's a potential it can lead to this sepsis in blood and bacteria in the bloodstream, unfortunately.

Stephanie Chisolm:

Thank you. Here's another good question. Are there any available things you can do to help your excess mucus and plugs that cause difficulties with a neobladder? But just in all the diversions, **are there any things that you see that work for patients in terms of diet or hydration that help to reduce problems related to the mucus that's inherent in using your intestines for getting urine out of your body?**

Dr. Anne Schuckman:

Yeah, this has come up I think all the time when we talk about this because patients always are worried that something's wrong if there's mucus. I guess I'd have two parts of this. One: mucus is a normal and healthy part of a urinary diversion. So seeing some mucus in the bag or in the toilet is normal. If it's causing problems with obstruction, the first solution is hydration, hydration, hydration, hydration. The more urine you're making, the more dilute that mucus will become and the less likely it is to cause a mucus plug. Two: if you have a neobladder and it's really a chronic issue, you may need to catheterize periodically and irrigate out the mucus. Some patients need to do this once a week just to keep the pouch a little bit more mucus free. Three: if you normally don't have mucus and all of a sudden you're having a huge increase in the quality of mucus, that actually can be a sign of an infection in a neobladder and so it may be worth a visit to a doctor to make sure you don't have something like a UTI, that can be treated with simple antibiotics

Eric Notti:

Can I jump in real quick? With a neobladder, when you first have your neobladder, you do expel a lot of mucus. When you first have a neobladder you do expel a lot of mucus to start with from the neobladder. As the years go by it lessens and lessens. So anybody, a new patient that has a neobladder is probably going, "What the heck is going on? How long is this going to go on?" Now at five year mark, generally speaking, you see a light silt at the bottom of the [bow] at the most. Except for myself, if I do any kind of heavy exercise, when I go play a game of golf or something like that, I'll have a little more shedding, but nothing like within the first year or two. It really goes away especially as Dr. Schuckman mentioned, you hydrate. You drink a lot of water, you cut back on caffeine hopefully, so that way the water will take effect and actually rinse you out.

But in my situation, now we're rolling into what, year six, like I say, I only have just a light silt and an occasional strand or two like I say, after going and doing some hard exercise. So for new patients, yeah, it's going to be a little upsetting. You're wondering what's going on. But as you get further into this, it will shed less and less and less. Or at least, that is my experience and I believe it's the experience of most people I've talked to with a neobladder.

Stephanie Chisolm:

Great. We have a couple of questions that are related to parastomal hernias. I'd love to get your input as the doctors. **Have you found that hernia belts can help, or is there anything that people should avoid doing in the sense of exercise, activity, or reaching?** Doing anything that they should be aware of to avoid or reduce the risk of developing a parastomal hernia that you've seen in real life practice.

Dr. Kamal Pohar:

Yes, Dr. Schuckman's talk had pointed out parastomal hernias, they can be common. They do occur. A hernia belt is a wonderful option. I have many patients of mine in the practice, a hernia belt or an abdominal binder to help. Whether they feel it's disfigurement or there's just a bulge or they have some degree of discomfort over that area. Or as the question asked, with activities they find that that becomes more bothersome. A hernia belt can certainly help fix a lot of those problems and I would certainly advocate that and encourage that. That if someone is physically active, exercising or doing other activities, a hernia belt is a very good solution. I wouldn't suggest that it should restrict your ability to do whatever you want in life. A hernia belt, I think is a great solution and can help you achieve what you want to do. Weight gain, unfortunately, which is hard for all of us sometimes to manage our weight.

But weight gain can be problematic with parastomal hernias, can exacerbate them. So trying to manage weight to the best of our ability, that can certainly sometimes be helpful.

Dr. Anne Schuckman:

Not a lot else to add. I mean, we talked a bit in the talk about prophylactic techniques. We use abdominal binders routinely after surgery. We have patients wear them for several weeks. And just for patients who are suffering with a hernia, many of the supply companies do make, what's the word I'm looking for? Individually sized pre-cut hernia binders with a hole for the ileal conduit. Customized is the word I'm looking for. You can send in your measures and I think there's a company called New Hope that makes those. Many patients just find they give extra support to the area certainly. Most patients don't come to having surgery for a parastomal hernia. For most patients, they live with the hernia and manage it conservatively. I think patients who we end up deciding to do surgery, it's a big deal and patients know that and so it's usually for patients who are really having problems with bowel obstruction related to their hernia, which can be a complication. Or they just simply can't fit the appliance appropriately on there because of the hernia on their stoma.

Stephanie Chisolm:

This has been phenomenal. I know we're coming up on the hour and Dr. Schuckman is still working because she's on the West coast and the rest of us are in the middle or to the East coast. So I'm going to close tonight's program. I want to thank you, Eric and Linda, for jumping on and being willing to share your experiences. Dr. Pohar and Dr. Schuckman, this has been fabulous and very informative. I know that people have really appreciated all the information that you shared.

