



Stephanie C.: Well I'm going to go ahead and interrupt a little bit and ask you some questions. The first question, and this might be a question for you, Jocelyn, what can I do to prevent a buildup of Blackish material in my leg bag? It looks like mildew or mold looks terrible and shows after a few days. Can you comment on that?

Jocelyn: A lot of times what we've suggested is, is it a one piece or two piece? If it's a two piece we've heard that before and they could be maybe some of the diet or maybe the medication. A lot of the patients have decided to use a solution of maybe one third vinegar and two thirds water and rinse the pouch. And the feedback from that is that that has helped some of the patients with that problem.

Stephanie C.: So another comment is, please talk about the discoloration surrounding the stoma, not obviously skin damage that you've already talked about, but just the dark halo. Is that common?

Jocelyn: For some patients that is common, what you really want to be worried about , and I guess my question would be how long has that person had the ostomy? My patients that sometimes have that, they're like maybe three or four years out and one patient that had the dark halo, they were wearing the appliance and it was too tight. We modified, we went to a lighter appliance as opposed to the deeper convexity that they were in. So dark halos could mean that it is too deep. And I'm not sure for this patient but normally when we see the dark halos, it's the appliance that happens. And so we just moved them to a lighter convexity.

Stephanie C.: The next question: can you go into a hot tub wearing a pouch? How does that affect the seal?

Jocelyn: It probably won't last as long. I have swimmers. So when they, as opposed to getting four or five days, they might get three. A hot tub, now remember the appliance, the wafers don't do as well in the warm. So if you're going into a hot tub a lot, then possibly your appliances only going to last three days as opposed to your normal five. That's what we've found in the past. So that's what we tell our patients.

Darrell: I actually do the hot tub, steam room and sauna every time am at the gym and I have no issue at all.

Jocelyn: You don't have any issues Darrell?

Darrell: No, and normal days between change times.

Jocelyn: Okay. So then it's an individual thing. The patients, some of my patients, there were time decreases anywhere from two or three days. So I think what's going to have to happen is that patient, that person we'll have to just try it and then see what happens with their real time.

Stephanie C.: So the next question I have is, is it possible for me to injure my stoma? If so, how? And how can I protect my stoma?

Jocelyn: It is possible to injure the stoma, there are some stoma caps, but you have to be really rough. Nobody wants an injury in the stomach. So I guess I'm asking, are you talking about playing sports or are you just talking about normal hurting myself? Remember the stoma is a very vascular structure. It doesn't have any nerve endings, but if you hit it too hard or something like that, you might get a little bleeding and you might get a little bruising.

I have a couple of teenagers who actually play sports. They use a stoma cap and they protect it, but they're like kickers. So I will say yes you can, but you learn. So it's hard to gauge that question. One lady had an animal, the dog likes to jump up on the front. She knew to protect that area because he was kind of heavy. So again, remember, think about if you're brushing your teeth or if you bite your inner cheek. That kind of mimics what the stoma is. So you don't want to get crunched or hitting it. But patients normally play basketball, they do the normal thing. They just know how to protect that a little bit. Darrell, any thoughts on that? Or Anne?

Anne: Yeah, I think you're just wear that it's there and you kind of protected a little bit. But keeping the bag close to your body, it doesn't really snag on things per se. So when you really damage it, I guess I get to dance quite a bit and I've taken a couple hits and I saw him a couple times then it really hasn't been a problem.

Darrell: And I wear a stealth belt pretty much all, so that helps protect it a bit. Be careful when you're walking and turning corners and whatnot, you know you're not going to bang into anything, it's pretty much no different than before.

Stephanie C.: Could one of you explain the difference between a one piece and a two piece? How do they work?

Jocelyn: The mechanism supposedly works the same. A one piece means the wafer sits next to your stomach and the pouch are one, they're all in one. If you see the Coloplast, the first pouch, the pouch and the wafer are joined together. Yeah, they're one piece. A two piece, you can have the wafer and the pouch separately and you put them together. My best example when I teach my patients is think about Tupperware. It kind of fits into that mold. But that's a two piece, your bag can pop off, but the waist, the one that protects your stoma stays on your skin.

Darrell: So if you look at the Hollister device you'll see kind of a double edge in the circle and that is kind of that track that attaches to the part that adheres to the skin.

Stephanie C.: Thank you all. So how do you handle itching that occurs along the outside diameter of the pouch wafer itself?

Darrell: Hope for it to go away.

Jocelyn: If there's itching then I would ask where you are having the itching, if it's not right under the pouch, that could be some other type of dermatitis or something like that. Normally when patients tell me they're itching underneath and I look, there is something like a little yeast or something like that and we just treat it with an antifungal powder and a spray. But I'm not sure about outside of the area where the wafer and the product is. That would have to be a visual to look at.

Darrell: And the one thing I notice is my skin is a lot drier in winter so I tend to have to lotion up. I have to be careful around the adhesives because you don't want any of that moisturizer getting under the adhesive.

Stephanie C.: So another good question that we have here, are there any risks for infection in the urinary system as a result of the stoma?

Jocelyn: Not because of the stoma, again, if you're going to get a urinary tract infection that is because of the bacteria in your urinary system. But the stoma doesn't cause you to get a urinary tract infection. I think that's what they're asking. So again, hydrating is going to be very important and then just looking for the signs and symptoms and that's what we teach our patients to hydrate and hydrate and hydrate.

Stephanie C.: Another question and we'll just get to a few more. Are there any good deodorizers for night bags or jugs?

Jocelyn: We just tell our patients to clean. There are products out there. What my patients have come back and told me was the water and the vinegar worked just as well, when cleaning them and making sure that they were clean properly.

Stephanie C.: And then I think we have time for just one more question. And this is going back to the beginning Jocelyn, you mentioned that would circle back to explanations of overnight options. Can you just talk a little bit about that since it is getting to be the end of the day and people might want to know, do they sleep longer or ensure that you have less risk of having any leakage at night?

Jocelyn: Coloplast has another night drain system. The jug that I showed was from ConvaTec and it actually sets on the floor because when we came to find that patients don't have anything to hang their pouch out of, but I have patients that have come up with a way and they really like the night drain bag and they hang it. They stick something on the side rail to hang on that. So we send them home with a night drain bottle.

A lot of my patients actually prefer the Foley that you're connected to when they come out of surgery. Or I have patients who like the leg bag and those are the three options that we send our patients with and some of them say that the night drain bottle, they can't turn the way that they want to. They don't

think it's flexible enough. And so again, individualized care, things patient what they need depending on them experimenting and using that. Darrell, you can tell them what you use and you might USE something very different than the night drain bottle also.

Darrell: So I use the the Foley type bag that I've had since surgery and cleaning it, all I do is rinse it out daily once I empty it. Anne?

Anne: And I use the ConvaTec jug as pictured because I can actually put it in a planter by the side of my bed when I'm not using it so it kind of stays covered. And then to clean it, I get a cleaner called uric clean and I just put a little bit of that in the tubing and it's a detergent and deodorant and it works very well and you don't really use that much. It's sort of like using dish soap for your jug.

Darrell: I forgot to mention that. The tips that I found was all I do is put a little tiny plastic cutting board with a handle hole and hang my bag from that between the box spring and the mattress. And that tiny little cutting board actually traveled really well. And so that's part of my supplies when I travel.

Jocelyn: That's very good Darrell and Anne, a lot of patients when they travel, if they're on long flights, they also like the leg bag so that they don't have to get up and do anything. So again, those three options are the offers that we our patients for containment.

Stephanie C.: Well thank you all so much. Anne and Jocelyn and Darrell, thank you for sharing. I think this was, I hope, a very important and great resource for patients and I very much like to get your feedback. I'd like to once again thank our sponsors for the webinars series, the Astellas Seattle genetics partnership, Bristol Myers Squibb, the EMD Serono and Pfizer partnership, Genentech Jensen oncology Mark and photo cure for their support of the patient insight webinar series.

