



Tips and Tricks for Managing Every Day Issues

Living with an IC

- Emergency Kit
- Travel
- Mucous
- Diet



Jocelyn: These are a couple of things that a lot of patients when they first, and even later on emergency kit. I teach my patients that no matter where they go, they should change whether it's a one piece, two piece and just keep a supply. It's very hot here in Texas. So I tell my patients do not leave it in the car because of the appliance and what it's made out of, it'll melt. So you always keep supplies with you. If you're traveling, dependent on the length or the time that you're going to be away. I always tell you to take possibly more than you need.

I have some one going away for two weeks. I said, well pack like you're going away for four weeks. The other thing would travel is TSA, will sometimes pat you down or have questions, there is a little TSA card that you can get to give to someone to the agents when they're traveling to let them know that you have an ostomy. So that if they choose they can take you to a discreet area and if they have to examine you, examine you there. So I'll let Darrell and Anne comment on the emergency and the travel kit before we go to the other two.

Darrell: The emergency kit definitely comes in handy. Travel, having TSA pre-check is a great deal. I had that pre-surgery but I've had no issues at all. And when you're packing your supplies, the wafers or pouches and whatnot, pack it in your carry on. Don't put it in your checked luggage, if you're checking luggage purely because in case that luggage is lost on, you don't want to be scrambling when you're traveling. Anne do you have any thoughts?

Anne: So as far as an emergency kit, I typically have like a gym bag in my car that has a couple replacements, if I have issues and the tape and also a change of clothes in my purse. I have one bag

available at all times and this is, we're talking three years since the surgery and I still am very cautious of having supplies with me at all times because it's a Murphy's law. If you have an incident or we call it "a situation" and you don't have your spare appliance, it's going to happen when you don't have it in your hand or available.

And then when I travel, I typically have everything in one location in the bag, but I also put some in the checked bag. So I have some in every single bag and like we stated earlier, bring doubles. So you would pack for four weeks if you are traveling for two weeks. That's a good rule of thumb. And as far as going and clearing through TSA, majority of the time they just pat search you and that I have not had any issues and I do fly frequently. And even going through customs, they didn't give me any issues with the scissors. So it's been very easy.

Jocelyn: I think the awareness that the UOAA organization, working with TSA, that's just got a whole lot better. But initially there were a lot of mishaps, but that the travel is getting much easier because now I think they're educating the TSA agents about people traveling that have ostomies.

On to the next point: mucous is a norm because they used a small portion ileum. It's normal function was to make mucus. Mucous is the lubricant that is in your GI tract. That's what helps move the food along, but we don't notice that because we sit on the commode, we go and then we're done. So just because it has a new function, it's still going to make mucus. A lot of my patients sometimes will notice that there is more mucus when they have a cough or the season changes, so they'll notice it then. Over time, my patients will sometimes state that the mucus becomes less, but in times of when they're having allergies again or if they have a cold will note that the production of mucus increases, but mucus production is normal.

For diets. the doctors here they ask that you hydrate very, very well. At least eight glasses or cups of water a day. Note that some food like asparagus, fish, onions, garlic, you might have an unusual odor when you go to the bathroom. Do you stop eating them? No. Just be aware that that's going to happen and a lot of my patients say if I know I'm going out, I just won't eat that during that time. So be aware that some things will give more odor.

Jocelyn: You'll also notice that if you're not drinking enough water, whatever you're drinking, that is what tends to be in your pouch. If you drink a lot of coffee when you empty, you smell coffee. So just note that what you're drinking, if it's not a lot of water to dilute it, you also see that in the pouch. So just be mindful that water is very, very important and to drink at least eight cups. Also you can look at some signs and symptoms of infection because if there is cloudy or foul smelling, back pain, nausea and vomiting or even blood there, that is a time that you want to call your doctor. So also be aware that that can still occur at times. Anne and Darrell, maybe thoughts on that?

Darrell: Yes, and one tip is if you notice that the urine is getting darker, it's one a sign of either you're not hydrating enough or sometimes I noticed with coffee it's always darker. I noticed a post on the Inspire blog recently and I noticed this in myself that you know occasionally there is blood on change day and it's purely because it the stoma was kind of reacting to the new capture.

Anne: Yes, I do notice the same issues. So when I see that it's very dark or there's a lot of mucus, I just tend to hydrate more. So that's the thing you have to be careful is to make sure you hydrate and I think that's what you'll hear mostly said by the medical community and by fellow ostomates. Just hydrate.

Jocelyn: Remember drinking water is very, very important to this portion in your life if you have a urostomy and again the color as they said, sometimes even more mucus production. You'll find that if you're not drinking, but you'll be able to tell because your urine should be yellow and clear. And of course you're going to have mucus like I said, but those are signs and again it's just kind of telling you, "Oh I need to drink a little bit more water."

We're almost at the end of the program, so let me just kind of go over basic tips. Some of the things that you kind of want to remember is sizing of your product is very, very important for maintaining and keeping the skin around the stoma clean.

The skin around the stoma should look just like the rest of your skin. So you want to make sure that you have a proper fitting appliance when you're using it. And you might have to change different appliances until you find the correct appliance for you. If there's ever itching or burning underneath your appliance, then you want to get that checked because possibly urine has leaked underneath your appliance you want to take care of that immediately.

Jocelyn: If you have a WOC nurse or a nurse that familiar with the ostomy and you need help with, you most definitely want to call that nurse. You want to hydrate and stay hydrated again, Darrell and Anne said, you will know if you're not drinking enough water because the urine most definitely let you know that. The medication also can change the color and the odor of your urine. But if you've noticed that it's a drastic change, you might want to let your doctor or your WOCN know.

And last but not least, the pouching system and the things that we talked about will depend on you and what you need to make the adjustments. We give you guidelines so that it fits into your life and so that you can have a good quality of life. And the main point behind this is that after the surgery, is for you to have a quality life so that you can get back out into the world and do the things that you love to do with your family and your friends. There are great support groups around.

BCAN is most definitely one of the top notch support options. You have the United Ostomy Association, but they have various ostomies. BCAN it's all urinary. So again, you have peers that can give you insight and help you with whatever you're possibly going through. Also remember that the companies that make these products, they have a responsibility of providing you with the resources as far as education and trying different products. So they are there and all of the ones that we mentioned have programs to help the ostomate have a quality life.

So don't feel like if you're calling them or asking them questions that you're bothering them, they have programs set up to help all of the ostomates get what they need and to help them through this process. We hope that's been informative and giving you some changes how to take care of your ileal conduit, your urostomy, your diversity, your urinary diversion. There's so much more information out there.

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