



The Care and Keeping of Your Ileal Conduit

Meet our Presenters

Welcome to “What you should know about the Care and Keeping of your Ileal Conduit, a chat with the experts.” You know that bladder cancer is a devastating disease with an estimated more than 80,000 new patients expect it to be diagnosed each year. For some patients, removing the bladder is the standard of care that offers the best prognosis. Today's program will focus on one of the common urinary diversions, the Ileal Conduit. My name is Stephanie Chisholm and I'm joined today by Jocelyn Goffney, radial cystectomy expert from the Houston Methodist hospital, along with two of our BCAN Patient advocates, Darrell and Anne who will share their experiences with the care and keeping of Ileal Conduits.



Jocelyn Goffney is a wound and ostomy and continence nurse at Methodist hospital in Houston, Texas. She's the program leader for this department, is responsible for assessing the needs, strategic planning and coordination care for patients with wounds, ostomies and continent issues. Additionally, she's responsible for providing staff education and serves on committees for the development of policies and procedures in the areas of wounds, ostomies and continence.



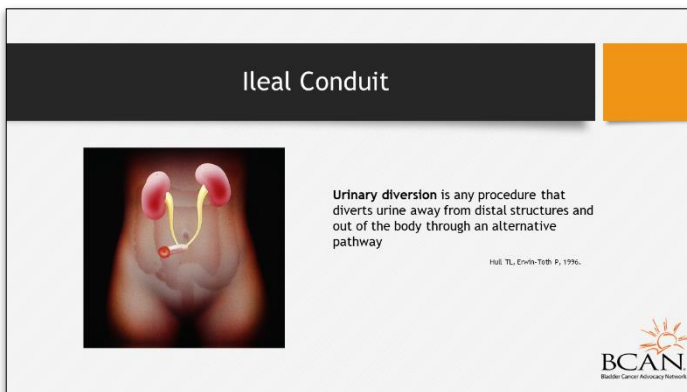
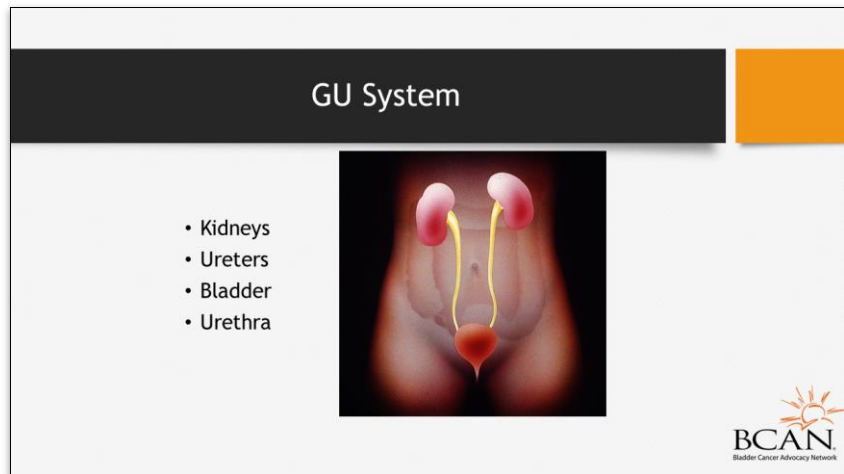
Darrell Nakagawa is experienced continuous improvement leader with decades of experience transforming corporations in different industries. He's quite the renaissance man. Daryl originally was destined for the operatic stage and as appeared with national and international stars, several QBs great performance broadcast in Hawaii, Houston and Cincinnati. And since his diagnosis in May of 2017 he's really continued to live a very active life and I'm really excited to have Daryl on board because he was diagnosed with T2 bladder cancer and had his bladder removed in May.



Anne Theriault spent many years with the Bureau of Prisons and retired from the US Army. She was deployed four times to combat zones and while there she began to take up ballroom dancing as a way of challenging all of the stress of being in combat in Iraq. Anne was diagnosed with a rare form of bladder cancer and she had her bladder removed with an Ileal Conduit six months before competing in the first Pro-Amateur ballroom dancing competition for the amateur dancer in Blackpool, England in 2017. Some of the people who've been on other programs and read other documents from BCAN have already met you in our newsletters, but thank you for joining us tonight.

Learning About Ileal Conduits and Common Issues

Jocelyn: Good afternoon everyone. I'm glad to be here. There are at least 1.7 million people in the United States or the world who live an active life after having an urostomy. I put the GU system up here because sometimes we just forget about how our bodies function. We have the kidney, which the ureters are connected into, which goes into the bladder, which then goes into the urethra. After you have an Ileal conduit or a urostomy, and you'll hear those two terms interchange a lot. The bladder is then removed and a small segment of the colon or small intestinal tract, the ileum. Mainly your small intestinal tract is used and this piece is used as the conduit for the urine you pass out of your body.



The ureters, as you see the bladder's gone, the ureters are then connected into the small intestinal tract, the ileum, and that is the way that urine flows out into a pouch. This is called a urinary diversion, but most terms you'll hear will be ileal conduit or urostomy.

The main thing that patients want to know when coming to see me preoperatively is "how do I know or do you know where to place it, where's it going to be?" A lot of patients think that it is going to be on their



side, on their back, but it's normally on the right hand side of your stomach. It depends on if you are

short waisted or you're a little taller. We come to the fact of where to put in by having you look at critical points on your abdomen. The stoma is usually constructed over the abdominal muscles. It gives it support, when the physician makes the stoma. We have you to stand, to bend and then we look and see is there any scarring, is there anything that would not provide a good fit for your stoma?

The questions that are often asked are: "how do I contain it? What do I do empty it? We tell you to empty when it's about one third or half full. There are containment devices, which you'll see a picture up a little later and most of your pouches have an anti-reflux valve. That means that when it flows into the pouch, it won't flow back up and you'd normally change it every three to five days. Anne or Darrell, would you like to add anything to that?

Ileal Conduit: Patient Education

- Emptying:
 - Stand vs. Sit
 - 1/3 to 1/2 full
- Nighttime collection
 - Standard bag (i.e. foley bag, leg bag)
 - Drainage bottle
 - Cleaning of equipment
- Pouch change
 - Antireflux pouch
 - On average every 3-5 days
 - Supplies




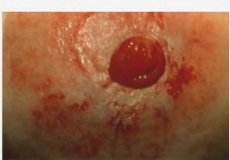
Anne: I would just add that when you're very active you may have to change it more frequently. So you might have to change it every few days or depending on your activity level.

Jocelyn: So you found three to five works very well and that's kind of a guideline and I just want to let everybody know that when we teach or we give information, it is a guideline. Your care will be specific to you. Normally when we start out, we teach survival skills and that's how to measure your stoma, how to apply the pouch to stay dry. And then we gradually worked your world way up to teaching you other survival skills so that you'll know how to manage your appliance.

Darrell: And you may notice when it is getting close to time to change. So what I notice is I have an increase of mucous in the liquid. So I know it's getting close to time to change. And there occasionally are seasonal differences. I can typically go longer in summer versus winter.

Ileal Conduit: Common Peristomal Issues

- Peristomal Skin Irritation
 - Poor pouch seal (leakage)
 - Poor stoma construction



Jocelyn: Yes. If you are a person that sweats or perspires, if you are a person that works outside a lot, your wear time will decrease. There are changes in signs with the appliance that will also let you know that it's possibly time to change it. Again, everybody's different and those are some really good thoughts. If you perspire a lot, if you are very active, if you're outside a lot, you probably will have to change your appliance a lot more frequent than normal. I stress to my patients when we talk about how they going to care for their ileal conduit. We talk about common problems


that'll happen. This is called a peristomal skin damage because you did not get a good seal. That is a typical stoma that you're looking at there. It is moist. It is red. Interesting enough, it has no nerve endings but it has a good blood supply.

Jocelyn: One of the complications is if your stoma starch turning dark, then the blood supply has been compromised and that is a call that should be made to your physician. The reason why there is peristomal irritation. It's either that there was a poor seal, which means that the pouch is not fitting properly. It can also be either that you're making the opening of the appliance too large or that you need to make a modification to your appliance. You'll find some of these complications in the first couple of months as you are getting accustomed to the appliance, but it's always important that if you start leaking, that you "tape" it. You have to start over with a fresh wafer.

You take the appliance off and you reapply the appliance because if you don't, what you're doing is trapping the urine under your skin and there's a picture of what happens if you trap it. And this is pseudoverrucous lesion, that means that there's a lot of leakage on the skin. So you get the skin reacting. It's like "I'm going to protect myself because this urine is constantly bathing my skin." How we treat this again is proper fitting of the appliance around the stoma, vinegar, soap, and they will use something called silver nitrate. It's like we have to reenter the stoma to decrease though that hyper granulated tissue around the stoma.

Ileal Conduit: Common Peristomal Issues

- Pseudoverrucous Lesions
 - Related to chronic leakage of urine on peristomal skin



Courtesy of Coloplast

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Darrell: Some people also use wipes, but you have to be cautious that the wipes don't affect the adhesive on the actual wafer.

Jocelyn: Definitely correct Darrell. What I teach or what we mainly teach is nothing that has any scent on it. We just teach cleaning with plain water, just plain tap water around there. We are usually creatures of habit and so even the mildest of soaps, if you're not careful, you can trap and so that residue underneath your pouch and then you'll get skin irritation occurring on that.

Darrell: That would include soaps like Dove or Tone or soaps that have moisturizers in it. So plain ivory would be best?

Jocelyn: Yes. And even with the plain ivory, we just caution you to really, really, really clean and make sure there is still no soap residue. That's when my patients really get into trouble is when they don't rinse that area really, really well and so they get like a skin dermatitis or an irritation on the skin. Some of the other complications that will sometimes happen is a peristomal hernia, and that's you have to remember that when you're in surgery they sometimes cut through the muscle and as we age,

everything kind of gets weaker and so peristomal hernia will sometimes occur with our patients.

Prolapse will sometimes occur and a retracted stoma. There are appliances that we use to help with all of these. Physicians normally will not treat

Ileal Conduit: Misc. Complications

- Peristomal Hernia
- Prolapse
- Retracted Stoma

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surgically because we again have appliances that can help with the hernias, with the prolapse, and with the retracted stoma. The only time normally they'll take you back to surgery is when there a decrease in the urine production and that is when they will consider taking you back to surgery to correct these problems

Darrell: I live with a Peristomal hernia on day by day. I use a Stealth Belt to help protect it and support it.

Jocelyn: Yes, there was a Stealth Belt and there are hernia belts by other companies and we will show you that. Also for the prolapse, for the retracted stoma , there is convex appliances and things that we use to help with that. These are the manufacturers and what I will say about the manufacturers is that all of these companies have a support person that can work with you. A lot of them often have nurses that they employ to answer questions. It's good to contact them through their website. They all have educational products that can walk you through changing your appliance and also that can help you with any questions that you might have. The other things that they will offer is samples of their products and as they improve on their products, they will also send the updated products to you.

They have newsletters that you can also get from these companies, so they're good resources to have if you're looking to try something different. A lot of times if I send my patient home with one company, I will get samples of others so that the patients can look at the variations and make a determination on which product best suits their lifestyle and what they would like to use. All of these companies also have charity programs that is, they will supply products to you free of charge. They have different requirements, but they're very, very simple if you're in need of getting a product.

Darrell: Well, each of them have a lot of different products based on your specific needs as well as one piece or two piece devices.

