

Zac Getty:

Afternoon everyone. Thank you all for joining us today for our Ostomate Questions Answered webinar. My name is Zac Getty and I am the patient education program manager here at Fight CRC. Fight Colorectal Cancer is the leading patient empowerment and advocacy organization in the United States providing balanced and objective information on colon and rectal cancer research, treatment and policy.

We are relentless champions of hope focused on funding promising high impact research endeavors while equipping advocates to influence legislation and policy for the collective good. Before we get started with the day's webinar, I have a few housekeeping items that I always like to go through at the beginning.

We'll have some time for questions at the end of this webinar, but please feel free to use your Q and A panel on the right side of your screen to ask any questions that come up along the way. We will do our absolute best to address them at the end. And this webinar specifically is meant to serve as an opportunity for you to ask your questions. So please don't be shy.

This is a great space to do that in and it's a good place to get answers. We'll have the recording of this webinar available on our site within the next few days. If you registered, you'll receive a direct link to that via the email that you registered with. We'll also provide a full transcript of this webinar on our site as well as the slide deck that accompanies the webinar today. Also, please feel free to tweet along with us. You can use the hashtag CRC webinar.

Please remember to stop by our website at [fightcrc.org](http://fightcrc.org) to check out all of our patient and caregiver resources. This includes your guide in the Fight meetups, which are an online space to meet with other patients and caregivers. They're held three times a month and touch on a variety of topics, but are also just a great place to find a sense of community.

We also have our free Community of Champions app where you can connect with other people in the colorectal cancer space and keep in touch with Fight CRC, and know what we're up to. And we also offer an assortment of print and digital educational resources that are free to request and download. And we are also now hosting monthly mega meetups, which address a specific and unique topic each month. Our next mega meetup will be on April 24th, I believe is a Wednesday, and it'll be focusing on women's health.

You can learn more about those in the Community of Champions app as well. I have a brief disclaimer for all these webinars. The information and services provided by Fight Colorectal Cancer are for general informational purposes only. The information and services are not intended to be substitutes for professional medical advice, diagnoses or treatment. If you are ill or suspect that you're ill, please see a doctor immediately.

In an emergency, call 911 or go to the nearest emergency room. Fight Colorectal Cancer never recommends or endorses any specific physicians, products or treatments for any condition. Okay, so with all of that out of the way, I'd like to briefly introduce our participants today. Joining us today are advanced practice colon and rectal surgery nurse Liz Rauh from Northwestern Medicine in Chicago.

Fight CRC ambassador, Kimberly Holiday-Coleman and Fight CRC ambassador and mentor, Michael Stern and Fight CRC, chief storyteller, Danielle Ripley-Burgess. Liz, Kimberly, Michael, Danielle, thank you all so much for taking the time out of your busy schedule to join us today. I'm going to hand it off to Liz and Danielle right now so Liz can provide a bit more information on her background and we can get into the actual webinar.

Danielle Ripley-Burgess:

Thanks Zac. Well thanks everyone for joining us. There's a lot of you today. So we see it's a really popular topic. And I'm so excited to have Liz with us. Fun fact, I've known Liz for a long time. We actually went to middle school and high school together.

And so when I saw that she was an ostomy nurse, I was just like, oh, the perfect person. So I'll have her introduce you, not the friend from high school I know, but Liz, could you tell everybody a little bit about your background and expertise?

Liz Rauh:

Yes, thank you Danielle and Zac for inviting me today. Very enthusiastic about this topic. I have been a nurse for a little over 18 years, so been doing nursing for a long time. Began working as a wound and ostomy nurse about eight years ago. I was drawn to this specialty because I knew a wound ostomy nurse and she loved her job.

She was very passionate about it. She felt very rewarded from her patient. So I knew something was in that. So I began working as a wound ostomy nurse about eight years ago and then really honing into ostomy care when I joined Northwestern's colon rectal surgery team three years ago. About a year ago I graduated with my family nurse practitioner degree. And so now I feel like I'm able to really provide care. I can expand my care to more ostomates around Chicago.

Danielle Ripley-Burgess:

That's awesome. Thanks Liz. I have a few questions for you just to dive in. The first one, just for anybody who might even be new to this, can you explain the difference between a colostomy and an ileostomy?

Liz Rauh:

Yeah, so both ostomy is kind of that general term meaning like opening. In this case we're talking about fecal or stool. So openings from the bowel. The colostomy as we see pictured here is an opening or disconnection from the colon, the large intestines.

So we're closer down to that end of that digestive track. Whereas an ileostomy is further up in the small intestines. So at the end of the small intestines is the area called the ileum, and that's where the disconnect in where that ostomy is created.

So frequently our ileostomy patients have a looser, thinner type of output, can see more output of that stool, and then a colostomy, one difference is that their stool, because it does have time sometimes to go through that hole, most of that colon see a thicker and maybe less amount of stool output.

Danielle Ripley-Burgess:

Got it. And I know sometimes these are permanent, sometimes these are temporary. So can you walk us through the cases? So two questions. When is it permanent and when is it temporary? And are both colostomies and ileostomies permanent and temporary?

Liz Rauh:

So both an ileostomy and a colostomy can be temporary and permanent. So some people think of, oh, if you have a colostomy, it's permanent. It's not the case. So the main things, what we're looking for here is their ability to reconnect.

Do you have enough of that? Basically, do you have some rectum and anus to reconnect? And that's what makes it temporary. If your anus is removed, then for some people that would mean that the ostomy is permanent. And then we also always think of what my surgeons often talk to patients with

when they're talking about reversals or having a temporary ostomy, for some patients, that's an elective procedure to decide to take down or reverse that ostomy. So some people think about that, is this worth having another surgery or is my quality of life okay having this ostomy pouch forever?

Danielle Ripley-Burgess:

Got it. So what would lead to someone getting an ostomy? What situations?

Liz Rauh:

So in my field, I see patients with rectal cancer, anal cancer, colon cancer, but I also see a lot of patients in the inflammatory bowel disease category. So our patients with ulcerative colitis, Crohn's disease, some people with diverticulitis that has perforated and just some patients with severe constipation or pelvic floor dysfunction. So a lot of reasons.

Danielle Ripley-Burgess:

Yeah. And then I think there's a few surgeries. So if somebody, I think we have a few pictures of different surgeries like a colorectal cancer patient would go through. So in all of these low anterior resection, would somebody automatically have an ostomy if they have a low anterior resection?

Liz Rauh:

It kind of depends on where in that rectum the cancer is. What I see mostly at my facility is that many patients who undergo this low anterior resection or what we call LAR do end up with a temporary ileostomy to allow that portion of the bowel so that rectum, that reconnection to heal. So typically at least a three-month temporary ileostomy, so that stool is not going through this area and allowing it to heal.

Danielle Ripley-Burgess:

Got it. What about the APR surgery?

Liz Rauh:

So this is typically used for low rectal cancers where we are not able to preserve that anus. So therefore those patients end up, you have both that abdominal approach to the surgery as well as your perineum or that anal area, so most of those patients end up with a permanent colostomy. And then also their anus is removed and that ends up with a surgical incision there that heals. So there's no longer an opening in that area.

Danielle Ripley-Burgess:

I think the patient term is Barbie butt and Ken butts.

Liz Rauh:

We hear that too. I usually read the room before I say those type of things, but yes, we say the same thing.

Danielle Ripley-Burgess:

Got it. Okay. Yeah, so patients have heard that, yes, and if you're on Facebook, yes, there's groups for Barbie butts and Ken butts, but okay, good to know. And then Liz, could you talk a little bit about general

ostomy and stoma care? So we're going to get into this a little more specific questions we have, but in general, colostomy or ileostomy, stoma care is a huge part of this and so general guidance?

Liz Rauh:

Yeah, so I kind of break it into two-pieces. I think of the part where you're emptying the output, so if that's an ileostomy, you're doing that multiple times a day, colostomy might be different types of pouches that we use, maybe even a closed in pouch. So I think of emptying and then I think of changing the whole appliance, which typically every three to four days.

So I kind of break it up into two things where things that you're doing every day to get rid of that waste, and then things you're doing maybe twice a week to remove that whole pouching system. And then when it comes to guidance from, hopefully many people have guidance from an ostomy nurse, I think of what's the shape and the size of the stoma.

I think of the contours of the abdomen and that's what I am helping give guidance on as far as what type of skin barrier I feel is appropriate to them, what type of pouching system, whether it be drainable versus disposable or those closed in pouches. And then a lot of the rest comes with patient preference.

Do you want a see through pouch? Do you want it to be clear? Do you want to filter or not? So it's kind of this of working with someone who knows a lot about ostomy products and then finding out what's going to work best for you. So that's kind of the end result, hopefully is that perfect combination of what's allowing you to return to the activities that you want to do.

Danielle Ripley-Burgess:

Got it. Well, thank you. For everybody joining us, we titled this Q and A, so we're going to have a lot of time for questions and answers. So Liz helped go over some basics and we're going to hear a couple stories right now from Kimberly and Michael, and while they're sharing, I want to encourage you to start putting your questions in the Q and A box so we can answer those. But Kimberly, could you tell us a little bit about how you became an ostomate and your ostomy story?

Kimberly Holiday-Coleman:

Yes. Hi everyone. I became an ostomate in November of 2015. I was diagnosed with stage two colorectal cancer in July of 2015. And as I was going through my treatments, my original treatments of chemotherapy combined with radiation, my colon was over radiated to the consistency of tissue paper. So I had a bowel obstruction and perforation.

I already knew that I was going to have a temporary ostomy for six weeks, but because of the bowel perforation obstruction and having to have life-saving surgery, they asked me to keep my ostomy for two years. So it was temporary. I have elected, I'm one of those people that Liz mentioned that elected to not have another surgery.

My quality of life was good with an ostomy, and so I chose to keep tootles. That's what I've named her. So my forever side buddy, and that's pretty much what led me to the ostomy of life. So I've been an ostomate for eight years, going on nine years this November.

Danielle Ripley-Burgess:

Wow. Thank you. And tootles for being here today. Michael, how about you?

Michael Stern:

Yeah, so October, 2019 diagnosed with stage four colon cancer and the doctor was world renowned and he said, "There's a 5% chance that I'm going to have to put in a temporary ostomy." So oh, no big deal, 95% chance I'm not going to have it. Of course, I woke up, had the ostomy, and it was shocking seeing that coming out of my body.

I could not look at it, I couldn't clean it. It was traumatic for me. Thank God I had my wife who would help me change it and clean it. And it took me about three months to actually look at it. The nurses were wonderful, give it a name, it'll help you become comfortable with it. So after probably four or five months, finally I got accustomed to it and it was a world of difference because once you accept it, it wasn't as traumatic.

But knowing that I have had this and I'm not able to go to the bathroom, it was a very, very, very big life-changing experience for me because I'm so used to being active and I was just scared to go out and be physical, going to the pool and taking showers. So after six months, that was fine. So I got a reversal. I rang the bell, NED, I was like, okay, great. This is over.

Unfortunately, it came back and I had the Barbie butt, the anas removed, the colon removed, and I had a temporary turn into ... I'm sorry, I had it reversed. I should have said that. My ostomy was reversed. So I was clean, rang the bell, came back and unfortunately had the surgery and now I have a permanent ostomy. But the permanent one wasn't as traumatic because I was already used to it.

And now I've become very accustomed to it. And anyone who feels that getting ostomy is going to change your life, yes, it will. But actually I've become more comfortable knowing that I can go on a plane now for four or five hours, I don't have to worry about going to the bathroom. It actually is a much easier experience, even though I would rather not have it, but I've become very comfortable with it.

And anyone who has a temporary one, who it may become permanent, it really is not as big of a deal as I think most people might think when they first get it. I went through about maybe a month or two of trying different appliances. Now I'm very comfortable. I have a two-piece and it's down to a science. I can clean it myself in about a minute and a half and do the change. It's absolutely wonderful. So that's my brief experience.

Danielle Ripley-Burgess:

Awesome. Thank you for sharing, Michael. And Kimberly and Michael, thank you for sharing. I wanted to have you guys on. I was telling them before we started the webinar, I'm almost at a year of having mine, personally. I have a permanent ileostomy, so here's a lot of ostomates on the call today. And it was stories like Kimberly and Michael's that gave me that confidence and found acceptance quickly.

So hopefully more people who've joined us today will feel that. Okay, we're going to dive into questions because like I said, we have a lot. So we had a few output questions come in. I think Liz, you already talked about colostomy output versus ileostomy output. I think we covered that a little bit. One thing I see come up a lot is the use of Imodium. Patients seem to have mixed reviews on if it's recommended or not. So Liz, what is your take on the use of Imodium?

Liz Rauh:

It was always going to be driven by your provider, but many of my patients do take Imodium. A reason not to is if you've had a history of obstruction like small bowel obstruction, then we are more cautious. But the number one reason after ileostomy surgery that we see our patients readmitted for is for dehydration.

So too much loss of fluid and electrolytes with that high ileostomy output. So we often do recommend taking Imodium. Each of the surgeons I work with has a little bit different starting point than how

much they'll increase to, but many patients take it before meals and at bedtime. And I do usually emphasize that it does work best if taken like 30 minutes before your meals.

Danielle Ripley-Burgess:

Got it. Michael or Kimberly, do you guys have any experience with taking Immodium?

Michael Stern:

Yeah, exactly what Elizabeth said. I take it every now and then. Sometimes it just comes on and don't know what, it was something I ate or if it was stress related, but that definitely makes a difference. So yes, I'm very familiar with that.

Kimberly Holiday-Coleman:

And I'm on the opposite end of the spectrum. I have obstipation, which is chronic constipation. So that is not my realm. Only for certain medications I have experienced it, but it's generally when they're introducing different medications.

Danielle Ripley-Burgess:

That's interesting. And Liz, I think we talked about this too, a little earlier, but do you think that's a difference between ileostomy and colostomy when it comes to the constipation versus diarrhea?

Liz Rauh:

Yeah, and I see that in the same what Kimberly's saying. Many of my patients with colostomies do titrate some type of either fiber supplement or MiraLax to help get that consistency so they're having stool output. The colon is the main source of reabsorption of fluid and electrolytes into the body.

So that's why, especially with patients who kind of have problems with maybe with constipation beforehand, they tend to have that afterwards too. So hydration and maybe some type of medication or over the counter product to help with that consistency.

Danielle Ripley-Burgess:

Got it. So another question that's come up is about pancaking, which is new to this world. Last year I was like, what in the world? I'll let whoever wants to jump in, jump in. A couple questions. So if somebody is newer to this, what is pancaking? Do both ileostomates and colostomates struggle with it? And then any tips you guys have for managing this remedies, anything like that?

Liz Rauh:

I'll let you start Kimberly.

Kimberly Holiday-Coleman:

Oh, I wasn't sure if you want to explain it, but for me, I do experience quite a lot of pancaking because my stool is rather hard and formed almost fossil like at times. And so when it's coming out it's more sludgy. And so instead of just dropping down into the bag because there's a hole in the ostomy appliance and then the excrement comes through and it's supposed to drop down into the bag, gravity is supposed to do its work, but when it is sludgy, it will not drop into the bag.

And so you might see ... you could tell an ostomate, by the way, those of us who are constipated by we're pushing it down even though we have the bag on, we have to push the stool down into the bag. We have to do the work for gravity. And so generally I've noticed that convex appliances can help with that because they will create that buffer. And Liz can speak more to that, but that's what I've found either a hard convex or a soft convex appliance and then just kind of pushing the stool down into the bag has been my experience.

Liz Rauh:

All right. So I'll just kind of touch base, go off of that. So yeah, it's just stacking of that stool on top of the stoma and it not moving down to the bottom of the pouch. So a couple of different things that I recommend. It does not all work for everyone. So again, like we talked about, some hydration and maybe taking some type of over the counter or whatever your provider recommends as far as type medication to help make a more soft consistency output.

The lubricating deodorant for our patients with colostomies can be helpful, so it makes the inside of that pouch slippery for that output to move closer to the bottom. Some people find that the filter, not having a filter kind of helps. So sometimes that filter works. Rarely do people say that it works too well, but the filter can create this vacuum suction in that pouch.

So sometimes just covering up the filter or getting a pouch without a filter, some people that say that helps. And kind of a different take on that is some people have found to put just a small rolled up piece of toilet paper in the bottom of the pouch and what that does is just break that vacuum seal so that that output can move to the bottom.

Kimberly Holiday-Coleman:

And if you don't have that to follow up on Elizabeth, super quick and I forgot, another trick I use is coconut oil or some people put olive oil in the bag, they just kind of do a little spray. And when it comes in it just kind of slides down the bag, pretty much reiterating what Liz said. So that's another trick.

Danielle Ripley-Burgess:

Michael, how about you?

Michael Stern:

Yeah, unfortunately I'm the opposite. I have it more liquidy, so I would just say if it's more liquid, sometimes at the bottom it would leak. So I put a clip at the bottom, one of those binder clips to make sure even though it's Velcro, sometimes that Velcro just loosens up. So having a clip at all times is very important.

And I know I'm going off-topic, but just because I have the floor, also a belt, like an ostomy belt to keep the appliance closer to your body, especially if you're active, it really helps, makes a difference because sometimes it's bulgy and with clothing it kind of protrudes out, so that kind of makes it a little bit closer to the body, which I know is off-topic.

Danielle Ripley-Burgess:

No, I think that's perfect and those are some other questions I want to get to as far as some of the belts and wraps and things like that. The other tip I'll throw in that has helped me with ileostomy is wearing a little bit bigger pants. So I found that after my surgery there was swelling and just getting used to the bag expanding, it would pancake more if my pants were tighter.

So hard for us gals to go up a pant size. That's been an adjustment, but that's one tip I'll pass along too. Michael, let's go with some of your question. I want to tackle your question and then we have a few that wrote in during live, but there are a lot of products out there and we'll get to products like specific ostomy care equipment here in a second, but Stealth Belt and Stoma Genies and other belts, what have you guys used? What do you recommend? Patients that are watching this, they're new, anything that's really helped you in that realm?

Michael Stern:

Just again, the belts I think are really important, especially if you want to become active. It's very easy for the bag to leak if it's not done properly and you can't have a nurse come to you 24/7 unless you really have experience, that one week could ruin your day.

So having the belts and make sure that you have the right appliance, even if you have to go through different companies, one-piece, two-piece, once you find that right fit, stick with it because I've heard people had to change their bag two or three times a day.

I can go a week without changing mine. That's how solid I am. I think I'm fortunate in that case because most people don't. But really if you are having trouble, there are so many different options out there. Just keep trial and error.

Kimberly Holiday-Coleman:

Yes, I have not used this self, but I've had a lot of friends that use it and they love it. I created my own out of shape wear at the very beginning. I don't really wear it so much now because I know after eight years, I know how I'm going to camouflage or make it more profile streamlined.

But for the beginner, say you don't get the Stealth Belt, you can get shaper wear and cut the bottom out. And that was my original camouflage that I would use to make my clothes more streamlined. So you can do things like that. The Stealth Belt, like the regular belt, I loved that regular belt.

I wore that for many years at the beginning that they give you this little tan belt. And it does help you to feel secure. Sometimes I'll use that when I'm traveling because I'm moving a lot. If I'm moving a lot or doing things, dancing, performing, doing those things, then I will tend to opt for things that will help me feel more secure like a belt or the little shaper wear thing that I created or just fashion, those types of things.

I feel like they really help a lot and they just give you more security whether you're being intimate or especially when you're being intimate at the very beginning, that's a concern. So those types of things just give you more confidence. So they're really good tools to use.

Danielle Ripley-Burgess:

Right. Liz, anything to add?

Liz Rauh:

No, I guess the only other thing is when it comes to more support belts, so whether it be you have a bulge or a possible hernia around your stoma, which can happen or you're very active and just want a little bit more support, active as far as you want to get back into maybe some lifting weights and things like that, I recommend a support belt. And there's one. New Hope makes a custom sized one that I think is wonderful for people.

Danielle Ripley-Burgess:



Awesome.

Michael Stern:

If I could just double down on that. About three months ago I went skiing and that belt was just amazing because it keeps everything together. And I almost forgot I had the ostomy because it really covers it and it really is a game changer. If you really want to be physical, that to me is a no-brainer.

Danielle Ripley-Burgess:

That's encouraging. I think even just people hearing you can ski with an ostomy, that's so encouraging.

Michael Stern:

People go swimming, I don't go swimming, but people do normal stuff and there are baseball players, Major League Baseball players that have an ostomy that you would never know. So you can live a very, very normal life.

Danielle Ripley-Burgess:

Absolutely. One thing I'll throw in on the conversation, I've seen sometimes people wanting to prepare for surgery and get a belt before, but some of the support belts are custom based on your stoma size and your waist size. So that's something. Don't go order a custom support belt until after surgery. Quick tip.

Liz, a couple of questions came in I think kind of geared toward a medical professional. The first one's actually about LARS. So why LARS isn't discussed with colon and rectal cancer patients before or after surgery. I think maybe a lot of people who've had that LARS surgery experience LARS. So any comments on that?

Liz Rauh:

Actually in preparation, I didn't prep much for this webinar since most of it's my day-to-day stuff, but I did look up some stuff on LARS just because I usually see the patients when they have their ostomies, but so LARS is that low anterior resection syndrome. So when patients get reconnected and they're missing a partial or most all of that rectum, you can have really no rectum and your ileum connected to your anus.

Those patients often, and I don't have the answer for why it's not discussed, I think all surgeons should tell their patients of this and a lot of the symptoms those patients have are, and they do get better, they can get better in time is like fecal incontinence, whether it just be passage like accidents of gas or stool, both of those, some urgency. So needing to get to the bathroom right away. Frequency, so having frequent stools and just the consistency of those stools.

So usually a looser bowel movement that is harder to ... it's harder with the incontinence. So I think all surgeons should talk about it. There are probably some, I don't know off of the top of my head the statistics of how frequent that can happen and it does get better in time, but it can take up to a year.

So just kind of putting that out to patients and understanding that some patients might just continue with their ostomy as a ... So having that kind of informed decision making together with the surgeon is ideal because some patients would, instead of undergoing surgery and maybe facing those problems would rather just keep the ostomy.

So also kind of awareness for professionals that, so surgeons and people on the surgery team that patients may prefer to have an ostomy instead of undergoing another surgery and facing those complications.

Danielle Ripley-Burgess:

Thank you. Yeah, we hear a lot from LARS, people suffering with LARS and sometimes they even say, I wish I would've known keeping the ostomy was an option. Kimberly, it sounds like maybe even that some of the decision making you went through is instead of the reversal ostomy life was actually better. Did that play into your decision knowing the possible side effects?

Kimberly Holiday-Coleman:

Yes, it did. I just naturally thought I would get a reversal after the two years because that's what my doctor said like, we just need you instead of the six-week temporary, we need you to keep it for two years in case some of the cancer cells sloughed off and you have a recurrence and then you would end up with a permanent ostomy.

So I said, "Okay, that's fine." And during that two years, during the course of two years, I started doing research. I joined some reversal Facebook groups and I just did a lot of research on it. And I felt like my quality of life was good. I didn't want to go through another surgery. All of that factored in.

It was just like the incontinence, all of those thoughts I had. And so it was just like I just sat and I waited over the two years. And it really gave me time to get enough information for me. And I felt comfortable with my ... I feel great about my decision.

So everyone is different. So it really is about doing a lot of research, joining the groups, hearing what some of their side effects, what they use for them. They're very informative, it's really good whether you choose to reverse it or not.

Danielle Ripley-Burgess:

Somebody else kind of anonymous attendee wrote in, I've been reversed and have LARS, recently discovered the Peristeen product. It has been very helpful. So sharing that with everybody. I haven't heard of that. Fong had a good question.

The providers often approach their initial ostomy conversation with patients with a negative view and patients take their emotional cues from them. How do we get more providers to talk about ostomies with the positive approach to help upcoming ostomates view the surgery and lifestyle with less fear?

Liz Rauh:

I think that might play a role with an ostomy nurse. So I have very close relationships with the, thankfully with the colorectal surgeons that I work with. They understand what I'm hoping for when they're creating those stomas. And it also helps that I meet with, unless it's an emergent surgery, I meet with all of the patients prior to surgery, not only to mark their abdomens for the stomas, but also just to kind of one, just introduce myself, say there's a team of us and I'm going to be the person that helps you with this ostomy.

So I think, I don't know how we can convince everyone to have a neutral take on the ostomy, but at least having hopefully our surgical teams and just the awareness of how much an ostomy provider can play in that role or know that the patients have either resources. It doesn't have to be an in-person ostomy person, but an ostomy nurse, but there's so many these support groups and even our

manufacturers of our ostomy supplies have wonderful resources for patients if they don't have contact with an ostomy provider in-person.

Danielle Ripley-Burgess:

Yeah. Thank you. I want to talk a few questions about equipment. We've already talked on this call about two-piece and there's one-piece. And for somebody who might be new or even not new, a couple of questions. Liz, can you explain the difference between two-piece and one-piece? And then I'd love to hear from Kimberly and Michael about which option you chose and why, or did you choose what you're using and why?

Liz Rauh:

So a two-piece ostomy pouching system, the pouch can disconnect from that skin barrier. Some people call it a wafer flange adhesive. So the pouch can disconnect from that. one-piece, it's all connected together. So when I tell, most of it's patient preference, do you change the pouch more often than you change the skin barrier?

Some people like that. So that would be more appropriate for a two-piece, pouching system. And then are you able to connect the two-piece pouching system? Do you have the hand dexterity? And then some people do prefer the one-piece pouch because it's a flatter profile and it provides some more flexibility. When we think of that two-piece appliance, we have that ring or that flange that's a little bit more rigid than say a one-piece pouch is going to be more flexible.

Danielle Ripley-Burgess:

Thank you. My patient's on the call. Thoughts on two-piece versus one-piece? Have you tried both? Have you just stuck with one?

Michael Stern:

Yeah, so I've asked that question numerous times to all my stoma nurses and I got the same answer. It really doesn't make a difference. It's really what's better for you? And I've tried both and to this day I can't tell you which one's better. I'm happy with the two-piece. It works. I don't change it that often, so if it's not broken, I'm not going to fix it.

But I don't think that there is a definitive answer. That depends on your body and maybe you have a need for a concave one, a non-concave one, maybe the wafer doesn't stick on a two-piece. So I think you have to have trial and error and whatever works for you, just stick with it.

Kimberly Holiday-Coleman:

I would agree. I would agree with Michael because I use a two-piece. I've used two-piece, one-piece, I used the Hollister system. That was my very first appliance in the hospital. And they send you home with this box of all kinds of appliances that you try and so you get to try different manufacturers and different appliances. And so Hollister, I use the Hollister two-piece. I have used the one-piece.

The difference I feel for me with the two-piece versus the one-piece, I like the ease of the two-piece because for one, I can look at my stoma. I can see my skin quality even. I can see if my stoma is bleeding or anything like that with the two-piece. With the one-piece, especially at the beginning it was harder because I couldn't see. You're kind of flying without that sight.

So for the two-piece, I like that. I really liked it at the beginning and I love it now. Sometimes I'll use a one-piece, but I still like to be able to see my skin. I still like to be able to see what my stoma is doing.

And it is just easier for me to use the product. With Hollister and I think with a lot of the manufacturers, they have different bottoms on it. So some are drainable and some are closed in pouches.

So for me, I used a two-piece closed in pouch. And if my stool is more liquidy then I'll use an open ended, one I can drain, a drainable pouch, I think that's what they call it. And so there's also short ones for more active lifestyle, short ostomy appliance for active and then longer if you're more active output.

So I really like all of those different possibilities because you don't really realize that at the beginning there's all these different bag possibilities. You get the first one and you just wear that and then you realize there's all these different options.

Michael Stern:

And the only thing I wanted to mention was opaque. When you can see through, when you can't see through, I choose not to see it. It makes me feel better, but if you need to see the consistency, if you're having problems, then the one that you could see through would be important.

Danielle Ripley-Burgess:

That's a good point. So we talk about trying different ones like flat versus convex, there's several manufacturers. Liz, if a patient was like, I want to try different things, what should that patient do? Is it up to them? Do they work with the nurse? How do you practically go about that?

Liz Rauh:

I typically help my patients request supplies. I can request supplies as a clinician on behalf of the patient. And I usually tell, they kind of tell me what ... we can even sample things as far as I want them to wear convexity because they're leaking. So I'll usually order appropriate samples from the manufacturer. And then the manufacturers typically send three of each product.

So that's when you can ask for clear pouches, ones with filters and whatnot. So they'll send the patient three to sample. I have patients and most of my patients in the beginning, they're more comfortable with me doing that, but I have patients who've had ostomies for either a long time or they're just ready to trial and error a lot of things early on in the process.

And then they feel comfortable going to the manufacturer websites and requesting those products. You can request samples from all of the manufacturers and they'll send them to your home to sample.

Danielle Ripley-Burgess:

Got it. Question Liz, on somebody was a Medicaid recipient. And kind of questions for Medicaid, Medicare patients, do they have any option, every option, or are there limitations?

Liz Rauh:

So most private insurance and Medicare kind of follow the same rules. So Medicare is a national program, so most patients are more or less provided 20 pouching products a month, when we're talking about drainables and the skin barriers. Medicaid is a state run program. So the patients, say the patients who have Medicaid in Illinois are unfortunately only allotted 10 pouching products a month.

So each state kind of varies and that's very unfortunate because we all know that you can't control if you are leaking and you need something. I will say though that, and it's kind of condensed on the United Ostomy Association of America's website, they have supply assistance programs though. So most of the major manufacturers have, if you're having difficulty getting supplies and paying for them, because they are costly when they're not covered by insurance, manufacturers have programs that you can apply for.

And there's also just organizations around the country that can provide supplies to patients in need. And sometimes it's just the cost of shipping. But as far as say you have a specific type of insurance, so you have your manufacturers, those are kind of the brands of supplies, sometimes what you're ordering from a supplier is substituted.

So I find that working with certain suppliers, they will not substitute, especially for those patients who have Medicaid insurance, whereas some of them will. So that's kind of a long answer, but sometimes if you're getting supplies that say you're used to using Hollister ones, how can I get that, sometimes it just takes either talking to the supplier on what they will provide.

Sometimes it's just instead of a flat skin barrier that's two and a quarter, they'll only supply the two and three-quarter, which could be maybe appropriate for some people or sometimes it just takes changing to a different supplier.

Kimberly Holiday-Coleman:

To piggyback that. Pardon?

Danielle Ripley-Burgess:

Yeah. Go ahead.

Kimberly Holiday-Coleman:

Hollister to further Liz's point, Hollister and they're different orgs, but Hollister in general, because I wear their product, they have secure start services. And then it's like they can walk you through the insurance side, they can talk with you about ... because I think they have, I'm pretty ... yeah, they have WOCNs on staff and so they can also talk through skin issues, things like that.

And it becomes more of a personalized thing. So you can end up getting, say you like Hollister products, you can get everything and it not be substituted out via your insurance. So maybe I would definitely echo Liz and say go directly to whichever manufacturer you like and see what program they have. And so for me that's the Hollister Secure Start.

Michael Stern:

One thing I just want to add. I use Edgepark, I think it's a middleman company, but when I sign up for Edgepark, they send me emails and they send me samples when they come up with a new product or based on what I ordered. And those samples are great because it kind of lets me test for free some different products. And I've actually ordered based on some of the samples I've received. I'm not sure if the manufacturers do that directly, but I would highly recommend you do that so you can try different things without having to break the bank.

Kimberly Holiday-Coleman:

They do. They do. If you go to Hollister or Convatec or any of them and you just go on, they usually will have new things and they'll say, hey, do you want to try it? And they will mail it out to you to try.

Danielle Ripley-Burgess:

Thank you guys. That's great advice. And so Cheryl is, she left a comment, this is actually the president of the ostomy ... one of our ostomy partners, UOAA, and she also mentioned we have free supply closets around the country with supplies for free for those in need. So Cheryl, first thank you so much for being on this webinar.

And yeah, I think both if you're in need of supplies or we get questions from time to time, how do I donate unused supplies? Maybe somebody had a reversal. We all know these are not cheap items, so they don't want them to go to waste. So I would just say as Fight CRC, we partner with groups like UOAA to help ostomates specifically find those closets, find how to donate, find local resources, and then things that Liz talked about too. I think ostomy nurses are huge. I think we all agree.

If you can find a specific ostomy nurse to help you navigate this lifestyle, there's nothing better. Okay, so many more questions. We have 10 minutes. We are not doing this topic justice if we do not talk about nutrition and diet in some way, although it feels like somewhat of a Pandora's box to open because I know it's a little different for everybody.

So Liz, can I start with you just for the whole community, I guess here's the first question, for the whole community, ostomates, ileostomate, diet nutrition, are there any tips that across the board apply to everyone in every situation with a stoma or is it really individual and different?

Liz Rauh:

So I'll say within those first six weeks of your postoperative period, we're going to follow your doctor's instruction. So ours is a low fiber diet regardless of type of ostomy. And then I really tell people that they can introduce those fibrous foods back on board after six weeks whether they have an ileostomy or a colostomy and it's going to be individualized.

I tell patients to literally start with a small amount. So if it's like blueberries you're missing, eat three blueberries and see how your body responds. And Kimberly and Michael can kind of more so specify of how do you know your body's not digesting this well?

But I usually tell people it's like a cramping, abdominal bloating type of feeling. You might see the output like the whole blueberry come out. So I usually say slow reintroduction of food and then always chewing your food well.

Michael Stern:

So I was traumatized when I first got the ostomy because they basically said, do not eat corn, do not eat seeds, do not eat skin. Good chance you can get a blockage. So from the start, I've been so careful because I did have a blockage about a year and a half ago and it was one of the worst experiences having that blockage. I had a tube go down, they cleared it.

Thankfully I didn't have to have any surgery for it. But ever since then I've been so careful. So the only advice I would give, and I don't want to take anything away Elizabeth said, she's obviously a professional, but from an individual standpoint is just chew everything as much as you can. When you think you've chewed enough, chew more. And then once you become comfortable with a certain food and you chew it enough where you know it works, put that on the safe side.

But if you introduce a new food, just be careful, even if you think it's not a big deal, just it's not worth it and eventually you'll get enough items that you're comfortable with. But to this day, I don't have beans, I don't have corn, I don't have grapes because I'm scared. I probably can, but I just warn people that everyone's body is different. So I would definitely go with the advice of your doctor or your nurse, but that's my personal experience.

Kimberly Holiday-Coleman:

And for me, I've been hospitalized. At the beginning when I had my ostomy, I was hospitalized very often with obstructions and on the verge of surgery quite often. And at least twice a year I was

hospitalized with obstructions. And because there's not a lot of information around diet and what you can have, they send you home with a low fiber and there's nothing else to follow up with that.

So for my recommendation, I would say keep a food journal. After you have your surgery, start writing down what you notice is slowing down your output and what is quickening it. When you just start writing like I introduced blueberries, it came out a whole, maybe that's a no. Now I can eat popcorn, but very little. I can eat certain things that I had that fear that Michael had.

I don't have that fear anymore because I started just being conscious of what I was eating and just kind of jotting down like ugh. And that has kept me out of the hospital with blockages. I still get them, but now I know how to navigate through them. So those types of things. Definitely contacting the WOCN when you have blockages or just even ... And a nutritionist. I think a nutritionist should be a major part of having an ostomy surgery. So maybe going outside if that's not offered by your hospital.

Danielle Ripley-Burgess:

I think that's great advice. Tips for getting in enough fruits and vegetables if someone's struggling with that. I think Michael, you mentioned a lot of what you're staying away from are healthy foods, beans and corn and grapes. And I know some people still don't do salad. LARS has issues with salad, but ostomates have issues. So any tips you guys have discovered or found or still struggling with that?

Michael Stern:

Yes, and I should have done this at day one. Almost every day I have a smoothie. It has all the vitamins I need and I don't have to worry about any kind of obstruction. It's a lifesaver.

Danielle Ripley-Burgess:

That's a great tip.

Kimberly Holiday-Coleman:

Definitely the hydration, if you can get the hydration packets. I don't do smoothies anymore because that was my sustenance being that I had colorectal cancer, so I'm smoothied out. But that is a wonderful ... I do recommend that. But definitely hydration, hydration packets, things like that that can ... anything that puts water into the stool, into your colon that will help move that transit through. That's a major thing for me. So yeah.

Danielle Ripley-Burgess:

We mentioned blockages. And Liz, any tips you know of that people can try and clear it on their own without or before they go to the hospital? I've seen tips online, but I'm curious from you, from a medical professional, what's legit?

Liz Rauh:

So this is what we tell patients. So most people can sense that partial obstruction or this obstruction coming on cramping, abdominal pain, no stool output and ileostomy versus colostomy. So an ileostomy patient who hasn't had output for 12 hours is a lot bigger deal than a colostomy.

So knowing your usual output, so no stool output or very liquidy stool output. What we tell patients is to just drink fluids, no eating. So just follow a clear liquid diet and we want you to hydrate quite a bit. Taking a walk usually gets things moving along. We tell the patients in a lying down position, it is like knee to chest movement.

So you're really just increasing that abdominal pressure to kind of get things moving. And then even a warm compress to the area around your stoma. Those things typically get things moving along. If not, then we recommend our patients to come in. Anytime there's vomiting, we want those patients to come in right away.

Michael Stern:

Let me just double down on what Elizabeth said. That's exactly right. I had that exact thing happen after my first blockage and I knew it was coming. I did exactly those three things and I was fine the next day. So 100%.

Kimberly Holiday-Coleman:

And for those who have, like for me, if you have a slower moving transit, then you might not catch it as quickly as someone with an ileostomy. And so it kind of builds over time. You're not realizing it. So some of the things or I use all those things listed. I'll go NPO at home and that's kept me from going into the hospital and I'll just use ice chips, not so much water because if you drink a lot of water at times on top of the blockage, it will create more gas and can create more of a volatile situation.

So ice chips, things like that. I do use a heating pad on my back, on my stomach. A lot of people use Coke, like a Coca-Cola at room temperature. Drink that. It will clear your pipes like a drain. Cat stretches, yoga, relaxing. When you relax when you're tense because of the pain, because of obstructions, the first thing they cause is a lot of pain.

So finding ways to get your body to relax and allow that to come through. So those types of things because I have weekly blockages so I'm an expert at that. So yeah, all of those things Liz said, Michael said, and adding on just everything you can find, talking to your WOCN of how to navigate that and going to the hospital when it posthaste because they'll help you more.

Danielle Ripley-Burgess:

Great, thank you. Well, I'm looking at time. I could talk about this with you guys for the next hour. We had some great comments even come in. Somebody mentioned if you're struggling to get supplies, see if your case management through your hospital might be able to help. So get a case manager involved either through hospital and or insurance.

And I will say the ostomy community is one of the most welcoming in the world. So if you need supplies and you need help, reach out. One more shameless plug for our partners at UOAA because this is all they do every day and so they have more webinars like this.

This is kind of one of our only ones of the year, but UOAA is all ostomy all the time. They have resources all around the country. So we really encourage you to lean into our partners over there and just get the help you need. Liz, I want to ask you kind of the final question. Just if somebody doesn't have access to a you, what should they do?

Liz Rauh:

Sometimes the surgeons have more ... yeah, they're well-trained on this. I could go to any of my surgeons and they can change a pouch. I don't know. And they can give some basic recommendations. Otherwise, I would just find someone virtually. There's an app called Ostomy 101. They have great resources.

So you could actually ... and just like what we talked about before, and Kimberly mentioned the manufacturers have WOCNs on staff. So just finding a resource for you that's going to be able to just



guide you through that. The manufacturers, like for instance, I know Hollister has one, they have four patients.

They have this assessment tool that you can tell them how much your stoma protrudes, what the shape of your body tissue around it, and they can give you suggestions on products to use. So there is a way to navigate it harder probably, and more time-consuming. It takes a little bit more for the patients to get out there and look online, but there are ways to find the right products by using those online tools.

Danielle Ripley-Burgess:

Great. Well thank you all. Michael, Kimberly, Elizabeth, or I call you Liz, thank you guys for joining this. I'm going to toss it over back to Zac to wrap us up. But one final note I am going to encourage our patients is it's a high value at Fight CRC to get you accurate, reliable information.

And I will say as somebody with an ostomy over the past year, even as somebody on staff with Fight CRC, I've been in a lot of online groups and I've gotten a lot of misinformation, even stuff that's contrary to what we've talked about today. So my plea is that if you're still looking for information and resources to really lean into the reliable stuff, the vetted stuff. Everything we produce at Fight CRC has been sent through medical professionals.

We have a community of champions where you can meet Michael and Kimberly and patients like us. We have people like Liz in our back pocket to help send questions through. So don't believe everything you see online, especially when it comes to an ostomy. Please make sure to lean into reliable sources of information and work with your doctors and your ostomy nurses because this is truly very individualized. All right, Zac, back to you.

Michael Stern:

If I could just have 10 seconds.

Danielle Ripley-Burgess:

Yeah.

Michael Stern:

If someone is new in this world and is about to get one or just got one, I'm listening to all this and it's very overwhelming, but I will tell you it is not as bad as you may be hearing. Once you accept the fact that it's part of you, once you get past that, it really doesn't have to control your life. You could control it. Don't let this overwhelming information scare you. In fact, let it help you adjust and become accepting to this new way of life.

Danielle Ripley-Burgess:

Beautiful. Thank you, Michael.

Zac Getty:

Thank you, Michael. So just to reiterate what Danielle said, all of Fight CRC's resources are medically reviewed by our medical advisory board, by medical professionals. Be careful with where you're getting advice from. We are a trusted resource. Some of the images earlier you saw came from our colorectal cancer surgery brochure, which is free to download, free to request.

We also offer a suite of additional materials. So I would like to give a big thank you to Liz, Kimberly, Michael, and Danielle for taking time out of your busy schedules. Liz, I know you're in clinic today, so

thank you for taking the time to meet with us, discuss this topic. Kimberly, Michael, and Danielle, thank you for taking the time to share your stories.

I really appreciate it. I like to wrap every webinar we have up with our mission statement, Fight Colorectal Cancer, we fight to cure colorectal cancer and serve as relentless champions of hope for all affected by this disease through informed patient support, impactful policy change and breakthrough research endeavors. Thank you to everyone who attended and thank you again to our panelists. Have a great day. Thanks so much. You have a strong arm, Sophie. I love it. I love it. Take care.