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### Introduction

**Stephanie Chisolm:** Radical cystectomy is the removal of a bladder to prevent bladder cancer from spreading to other parts of your body. And adjusting to this what we call new normal after a radical cystectomy, can be a real challenge for some people. Yet BCAN knows that most individuals continue to live robust and active lives, even without a bladder. Today we're delighted to have Dr. Michael Diefenbach PhD from Northwell Health. He is a behavioral scientist, and he's going to have a conversation with us about some of the common concerns that may arise after bladder removal surgery. Dr. Diefenbach is a professor in the Department of Medicine, Neurology, and Psychiatry at the Donald and Barbara Zucker School of Medicine at Hofstra Northwell. And he's the head of the Center for Health innovations and outcomes research. Dr. Diefenbach, it's a pleasure to have you with us. So I'm going to go ahead and turn this over to you, and you may start your presentation.

**Dr. Diefenbach:** Thank you very much. Thank you very much for the nice introduction, and the invitation to share my experience with the psychosocial issues after bladder cancer. We have developed a program for bladder cancer survivors and their caregivers at Northwell Health that we are currently testing. This is a study that has been funded by the National Cancer Institute. The purpose of this study and our program is to help bladder cancer patients and their caregivers with recovery after bladder removal surgery. Patients and their caregivers face many challenges after their surgery. And these challenges may negatively affect their physical, social, and emotional well being. But it doesn't need to be that way. This program and this webinar are designed to help you face these challenges, and as Stephanie mentioned, live productive lives and happy lives.

So let's go about some of those issues. So the talk is divided into two major parts. One is directed at patients. The other one is directed at caregivers. There are many psychosocial issues that I have mentioned here, and that we will be discussing in the hour ahead. And similarly, for a caregivers, there are a number of issues that are pertinent and that many caregivers need help with or might want to have addressed. And these are getting organized or managing medications, talking about cancer, a number of these kinds of things. So let's move ahead and talk about it.

As you heard last week, there are three different kinds of surgical procedures for a diversion. And the first one is the ileal conduit. And what that means is that you have the bladder has been removed, and there is a stoma that is on your lower abdomen. And after surgery, this stoma might feel, might be small, and there might be some achiness for quite some time. Over time, your stoma will shrink to its permanent size, and it will remain, if it's healthy, moist and shiny. At the beginning, the stoma may occasionally bleed. So it's important to be very careful when you're touching it. And of course, you always want to wash your hands and take care of basic hygiene.

What many patients will receive is that they will have an external bag band that will be attached to that stoma. And there are two different kinds of bags; there's one piece or two-piece system. On the one-piece system, everything is in one apparatus. And it's a combined bag with an adhesive section that attaches directly to the skin around the stoma. And this entire section

## Psychosocial Issues

What to Expect After Surgery

Care and Troubleshooting

Diet

Bathing & Hygiene

Getting Dressed

Sleeping

Pain Management

Recreation and Exercise

Travel

Emotional Health

Intimacy

Finances



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## Psychosocial Issues: Caregivers

After Surgery

Getting Organized

Managing Medications

Emotional Awareness

Coping Skills

Talking About Cancer

Time Off From Work



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## What to Expect After Surgery- Ileal Conduit

- Patients may have a swollen stoma and feel some achiness for a few weeks.
- Stoma will slowly shrink to its permanent size and remain moist and shiny thereafter.
  - Stoma may occasionally bleed, so it's important to be very careful when touching it.
- For urinary diversion: Patients may have either a one-piece or two-piece system.
  - A one-piece system is a combined bag and adhesive section that attaches directly to the skin around the stoma, and the entire assembly is removed each time the bag is changed.
  - A two-piece system separates the bag from the part attached to the body, which means you can change the pouch without removing the adhesive section from skin.
- Patients should empty their pouch when it's one-third to half-full and change their pouch every 3-5 days.



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or assembly is removed every time you change your bag, and you change it about every three to five days. The two-piece section is slightly different. You have a piece that is attached around to the stoma, and then the bag is screwed on to it. And you can then, when you fill it, it's easier to take it off. And so there is no right or wrong way of choosing which one is worse, they work both equally well. And we always tell patients that they should experiment with these appliances and figure out what they're most comfortable with. And there are ways that you can try them out, and see how they work for you.

**Dr. Diefenbach:** So the other major component is the Indiana pouch here, as I'm sure you all know is that there is a artificial pouch being reconstructed from a colon tissue it resides inside your body, and there is a small stoma, an exit, that protrudes, and that you can then catheterize to empty it. When you get out of the hospitals, you will see that there are a number of tubes coming out of your abdomen. Often they are combined with the drainage bag. And those tubes help you to prevent strain on the pouch, they facilitate urine flow, and they support the safe healing until you really feel comfortable doing it all yourself. Over time, these tubes will be removed. The surgeon will ask you to come back to the office, and they will lead you through this and teach you throughout the recovery process.

Because the pouch is made out of colon there is the possibility that mucus will be accumulate inside that can create blockages. So you need to make sure that when you're ready at that point, that you rinse your pouch in regular intervals, and that the catheter is clean, and that everything around the stoma is healthy. So those mucus accumulation can be prevented by rinsing the pouch. And if you cannot drain from a catheter or if the skin around this stoma becomes irritated or red, or if the stoma starts to bleed, then that's a good time to call a doctor. You might also have access to a visiting nurse. And sometimes those visiting nurses are trained in stoma care. That would be a great resource to call that support system on. When you get out of the hospital but initially you will have a bag, a drainage collection bag that is attached to your legs as you can see on the lower right hand corner. And at the beginning the pouch and the bag needs to be drained very, very frequently. And with time, the pouch starts to become bigger and bigger, and you don't need to drain it as much.

### What to Expect After Surgery- Indiana Pouch

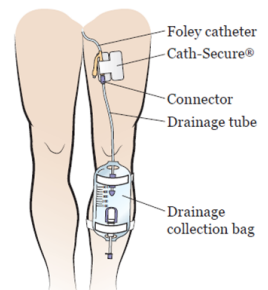
- Patients may experience a swollen stoma. Stoma should not hurt, maybe some achiness.
- There may be various sized tubes coming out of the abdomen, often combined with a drainage bag.
  - Tubes help to prevent strain on the pouch,
  - facilitate urine flow and support safe healing.
  - Tubes will be removed in stages throughout the recovery process.
- Keep the pouch drained, catheters cleaned and skin around the stoma healthy.
  - Prevents mucus accumulation that can create blockages.
- Contact a doctor if:
  - Little or no urine drains from the catheter,
  - the skin around the stoma becomes irritated,
  - the stoma starts to bleed.



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### What to Expect After Surgery- Indiana Pouch

- A few weeks after surgery, doctors will test whether the pouch system is working properly, is healing and is not infected.
  - Instructions to self-catheterize will be provided.
- At first, pouch needs to be drained very frequently- about every 2 to 3 hours.
- With time, pouch will stretch and will usually need to be drained every 4 to 6 hours.



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The third option is the neobladder. Neobladder is fashioned again out of colon tissue. There is no stoma, the usual exit is preserved. And again, when you leave the hospital, there are a number of catheters and tubes and stents that are being placed in your body. And those will all help you to set the neobladder, the bladder that is formed that the surgeon has formed, will properly heal. Remember that the neobladder will not have nerve endings. There will be no feedback when your

bladder is full, and you don't have any voluntary control over the bladder. So you have to learn a new way of voiding urine that is collected in there. At the very beginning, again, the nurses will show you how to properly take care of all of the catheters. Also at the very beginning, careful walk and stand up. Movement is always important because you want to make sure that you don't develop any blood clots. And then there's urinating, this new way of urinating is called the Valsalva maneuver. And it is a form of abdominal straining that you can often times are advised to learn and to practice even before surgery so that your muscles are strong. If you can't, or if you are not successful in voiding, then there is the option that you would have to catheterize yourself or somebody else might need to catheterize you and through the existing exits. And that is what is happening with the neobladder.

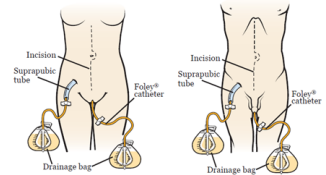
So now let's talk a little bit about things that you need to think about in terms of care and potentially troubleshooting. So for the ileal conduit as I said before, there might be some swelling, redness, or rash around the stoma. These could be signs of infection, especially if there is some pain and redness involved or if there is some fluid coming out of this stoma. As I said before, this is a good time to talk to a healthcare professional. You can also apply some antibacterial ointment around the area. And what is also quite common and normal is that there might be some leaks within the first year or so after the surgery. So what you should think about is that you empty the pouch until it has a regular size and until you know exactly how long it takes to fill up that you just empty it out on a schedule. And that could be as much as every two hours, it could be three to four hours. The intervals will definitely increase.

## What to Expect After Surgery- Neobladder

- For about three weeks after leaving the hospital, patients may have devices in place, such as catheters, suprapubic tubes, and ureteral stents. These devices will help drain urine from the neobladder.
- Nurses will show proper care of these catheters (flushing).
- Careful walking and standing up is important to avoid blood clots.
- Once catheters are removed, patients can begin urinating using the Valsalva maneuver.
  - Valsalva maneuver, a form of abdominal straining.
- Neobladders do not have any nerve endings, no feedback when the bladder is full. Can result in leakage, especially at night.
  - Self-catheterization, might be necessary.
  - Normal to see mucus in the urine.



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## Care and Troubleshooting- Ileal Conduit

- Swelling, redness or a rash around their stoma.
- Signs of infection include redness, tenderness and pain, or white or beige fluid around the stoma.
- Leaks are common in the first year after surgery.
  - To avoid leaks include emptying the pouch when it's less than one-third full,
  - Tight fitting skin barrier
  - Use supplies as instructed.
- Odors are a common and sensitive issue.
  - Most pouches have a barrier that helps contain bad odors.
  - Foods can affect the look and smell of urine.
  - Drinking a lot of water and beverages without caffeine, such as cranberry juice, helps decrease odor.



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**Dr. Diefenbach:** For many people, odors are a common and sensitive issue. There are the pouches have a barrier around it that helps contain odors. But you can also have some control over odors just by what type of foods to eat. And if you drink a lot of water, and this is something that a lot of patients feel is counter intuitive is to say, "Well, if I drink a lot of water then I produce a lot

of urine, and then I have to drain it more often, and that's a hassle," and all of these kinds of things. Well, drinking a lot and keeping everything flushed really helps. It helps with odor control, it helps with preventing mucus built up. And as long as you drink water or beverages without caffeine, we mentioned here cranberry juice, that is very healthy, and it helps with some of the odor issue, and also with some of the mucus buildup. For the Indiana pouch areas, around the catheter, the Jackson Pratt drain that is on the stent might become irritated right at the beginning. So again, use antibiotic ointment. After you come out that you see a lot of bruising, that's normal, it will clear over time. And again, moving around is really good for you at that point.

If you have trouble inserting the catheter, there are a couple of tricks. And there are also videos on the internet that you can see. But one of the most important things is that patients who we have talked to is that relax your abdominal muscles. If you are tense, if you're worried, if you're anxious about this, you tense up and that's very counterproductive. With time, you don't even need to look down anymore. And so that's also good because then your

muscles don't contract that much. And then take some deep breaths and try to relax. By the way, all of those things that I'm telling you about are culled from many interviews that I and my colleagues have done over the years. And these are things that patients have told us. We have done countless patient interviews, countless focus groups, where we have taken out these pearls of wisdom that patients have told us, and we have them all put together in this presentation and in our program.

So if the catheter is clogged with mucus, then this is really high time to irrigate it with some saline. You also can gently slide the catheter back and forth. And you might also think, well maybe something

### Care and Troubleshooting- Indiana Pouch

- If catheter is clogged with mucus:
  - Irrigate with saline to thin mucus,
  - gently slide the catheter back and forth
  - completely remove and reinsert the catheter may help with urine flow.
- If you experience increased urine frequency and leaks, catheterize more often.
- It's important to stay hydrated and drink plenty of fluids, to prevent urinary tract infections and decrease odor.



### Care and Troubleshooting- Indiana Pouch

- Areas around the catheter, Jackson Pratt drain, and stents might become irritated.
  - Apply a thin coat of antibiotic ointment, 3 times a day
  - Bruising is normal around the incision sites and will clear over time.
- After surgery, the stoma and surrounding area are swollen. This is normal, but it can make draining the pouch take longer. Change your position—sitting, standing up, lying down.
- Trouble inserting the catheter.
  - Relax your abdominal muscles. Tense muscles prevent insertion.
  - Don't look down as the catheter is inserted, this causes muscles to contract.
  - Take some deep breaths or look up at the ceiling while inserting the catheter.





doesn't, it's not quite right, you might have to take it out and then put it back in again. If you feel that if you drink a lot there is more accumulation of fluid, you have to catheterize yourself more often. Again, it does not hurt. There are no nerve endings in there. So it is just a way of... And you will get... Everybody gets used to it, but it is just a way that is something that you have to learn, and you will become proficient in it.

For the neobladder, again, when you come out of the hospital, you have irritated skin, you're still bruised, there's swelling around the incision sites. I mean you just went through major, major surgery. So, it is very normal that you feel as if somebody... You come out of a very, very physical hard experience. So again here, drink plenty of water. Irrigate to reduce mucus production and clogging. And frequent leakages are, at the beginning, also common. And once the new bladder establishes its stents a little bit, it will become less and less so, and you will have fewer of those leakages.

So what can you do if this happens especially at the beginning? Well, the best thing is to stock up on rubberized sheets and mattress covers that protect the bed. And while you are sleeping or resting, these things are very, very good. And you can just exchange exchange them as needed. You might also wear absorbent underwear or pants. Depends products are very commonly used.

And try to urinate frequently, especially before bed and before travel. And don't be surprised if there is some urine especially right after surgery in your urine. If there's some blood in your urine, that's very common. But if it stays on for quite some while, then that could be a sign of urinary tract infection. So you have to monitor that little bit.

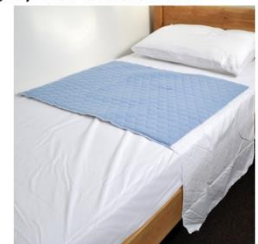
### Care and Troubleshooting- Neobladder

- Irritated skin, bruising and swelling around incision sites.
- Also common: Too much mucus production and clogging.
  - Drink plenty of water and irrigate with a catheter often can prevent mucus buildup and potential clogs.
- Frequent leakage at first are common.
  - Once neobladder heals and stretches to full size this will be less common



### Care and Troubleshooting- Neobladder

- Plastic or rubberized sheet and mattress covers can protect the bed while patients heal and get used to the new bladder.
  - Hospital pads are also a good alternative.
  - Absorbent underwear or pads, such as Depend products, offer mobility.
  - Urinating frequently, especially before bed or travel reduces leakage.
- Some blood in the urine is common, especially right after surgery. But this also can be a sign of a urinary tract infection or other issue.



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