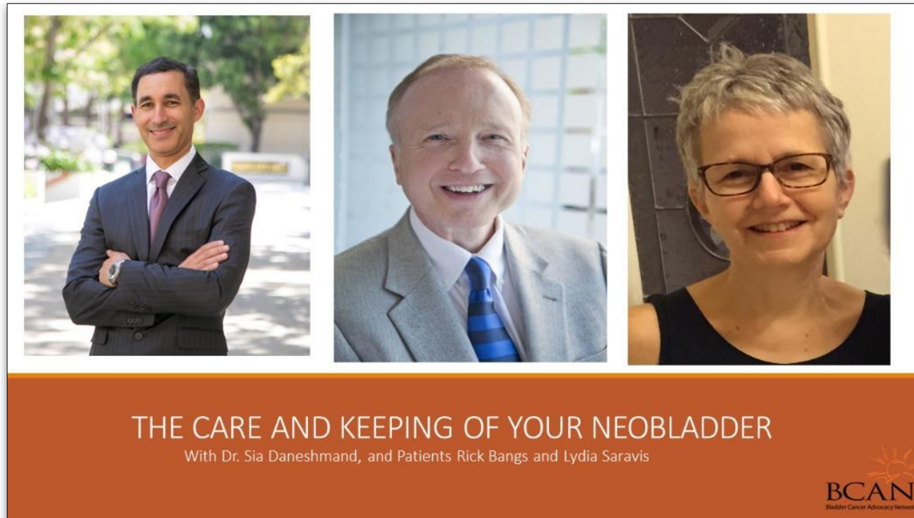

Rick Bangs:

All right. Okay. So Lydia and I are thrilled to be here, and we're going to talk about care and keeping of your neobladder. So we're really talking about what it's like to live on a day to day basis with the neobladder from this point forward. Okay. So I want to start with some rules of the road. So one thing that's, I think pretty clear from what you've heard already and you should continue to keep in mind is that your mileage may vary (YMMV). In other words something that is true for me may not be true for Lydia or true for you as well. We've already gone through the wonderful engineering marvels that is a neobladder in the previous section.

Rules of the Road

Rules of the Road

- YMMV (your mileage may vary)

Agenda

- Specifications
- Test Drive
- Break-In Period
- On the Road [Again]
- Tune-ups and Inspections

BCAN
Bladder Cancer Advocacy Network

Rick Bangs:

So we're going to talk a little bit about test drive. That will be a very brief conversation. Then we're going to talk about breaking period where there's a lot of conversation. We'll talk about what it's like after the break in period, and then talk about tune-ups and inspections. All right. So from a test drive perspective there are a number of institutions that will have you test drive an ileal conduit. They'll have you wear a wafer and ileal conduit. But with a neobladder, you can imagine that that's really not going to be possible. It's all internal mechanics. And so that's not going to be feasible. But there are some institutions that may recommend or support patients test driving the self catheterization because there maybe some concern about that and making sure that that patients are comfortable doing that. So there may be some test driving as far as that's concerned.

Test Drive

- Not feasible to truly test drive.
- Some institutions may recommend or support patients test driving self-catheterization.

Lydia Saravis:

Thank you, Rick. I'm going to review the break in period during the first three months post-op and in this first slide regarding post-surgery. So you will come home with a Foley catheter for approximately three weeks. You will notice mucus in your urine, which is normal. Typically if the volume of the neobladder increases, there will be more dilution of the urine and mucus will be less noticeable. It's important to note that when you have a Foley catheter after neobladder surgery, including after any subsequent surgery, the catheter will need to be irrigated periodically to prevent blockage from mucus.

Break-In Period (3 months)

Post-Surgery

- Foley catheter
- Mucus ("egg drop soup")
  - occasional clumps
  - volume change across time/dilution with more urine capacity
  - Irrigation with sterile saline, particularly with Foley catheter
- Small Bowel Obstructions are a possible surgical complication.
  - Severe abdominal pain with or without nausea that doesn't wane should be reported immediately.

Sometimes after abdominal surgery, some people will have a small bowel obstruction. This is due to adhesions or scar tissue forming in the gut and causing a blockage. Symptoms are severe pain that persists sometimes with nausea or vomiting and medical attention is needed for treatment.

So after the Foley is removed at about three weeks, the neobladder capacity will be small. Over time it will increase to contain approximately 400 to 600 milliliters, and that does vary.

Lydia Saravis:

Some patients will be asked to continue to irrigate their neobladder, and this will be done with an intermittent catheter. The catheter can also be used to check residual urine in the neobladder after voiding.

Some patients may be asked to use a catheter to routinely empty their bladder. And it is important during the recovery to stay hydrated, to avoid mucus plugs, which make it harder to empty the bladder.

Break-In Period (3 months)

Post-Foley (about 3 or more weeks)

- Capacity range (post-surgery)
  - Starting at 150 ml to eventual 400-600 ml (varies)
- Self-catheterization
  - Irrigation with sterile saline
  - Measurement of residual volume after urination along with self catherization may be suggested
- Hydration to avoid mucus plugs

How to void? So there's a lot of variability and voiding techniques. Men can sit, stand, lean, or a combination of all three. Women will sit as before. Some push, some relax. So what that means is learning to relax the pelvic floor and incorporate breathing into the voiding technique can help with successful voiding. The Valsalva incorporates pushing and Crede includes combined manual pressure with leaning forward.

Break-In Period (3 months)

How to Void

- Males: sit or stand or either
- Some people "push" . . . some people "relax."
  - Relaxation and breathing techniques
  - Same muscles used if you were trying to urinate as quickly as possible with a bladder
  - Positional and other enablers
    - Valsalva maneuver
    - Credé maneuver

Complete emptying is important

I personally combine elements of both those maneuvers plus drawing in my abdominals while simultaneously exhaling. With time, it has become a seamless process and it is important to fully empty the neobladder. Towards that end, some people find guidance from their physical therapists with pelvic floor training, to be helpful in maximizing their voiding ability.

Break-In Period (3 months)

Sensation to void varies. Indicators that "it's time":

- Some have feeling of pressure or minor discomfort
  - Similar to gas pain/bloating
- Some have a return to sensation almost same as "before"
- Some have flank pain (ureter reflux)
- NOTE: some have no sensation at all

Sensation to void are the cues that it's time to void can vary from person to person. Some people feel pressure or discomfort like gas pain, some will feel a sensation similar to before, but less pointed. Some people might have flank pain when their neobladder is full and some people will have no sensation and will need to be mindful of the time since their last bathroom visit.

Lydia Saravis:

So building capacity with time voiding. Instruction for tiny bathroom visits after Foley removal may vary. Typically the goal that is given us to go two hours between voids. In the beginning, I was lucky if I could wait 15 or 30 minutes. With time though, the interval increases with gradual improvement measured in weeks, not days. Ultimately most find they can go several hours between voids, depending on beverage intake. Personally, I find I'm most comfortable with a voiding schedule of between two and four hours. It can be helpful during this time to consult with a physical therapist, with pelvic floor training who can devise a program of pelvic floor muscle exercises or kegels to help strengthen the pelvic floor muscles, which in turn can help with regaining continence. And now Rick is going to present the next group of slides.

Break-In Period (3 months)

Building capacity by urinating at set time intervals ("timed voiding")

- Procedures vary by institution
  - All start with a shorter time interval, typically 1.5-2 hours
  - Increase gradually over a period of weeks, adding a time increment each week.
- Final intervals are somewhere in the 4-6 hour range

This process can take a few weeks or months. Patience is key.

Rick Bangs:

Okay. So we're going to talk about getting back on the road. As Dr. Daneshmand pointed out, continence is a continuum, and in other words you can be continent or incontinent, but incontinent has different levels. And so there's some things to do that you can do to help manage your continence. So you may need to do some adjustment of the timing of your fluid intake, and some people will taper or stop during the evening in order to get through the night without having any problems. Caffeine and alcohol may impact your output and their continence levels.

The Neobladder "On the Road, Again"

Urination

- Takes longer
  - May require double voiding (void, walk a little, void again) to completely empty
- Flow is less constant and suddenly stops
- Less accuracy
- Mucus continues
  - usually the first part of urine stream
- Requires "work" (active not passive)

Rick Bangs:

And there's different techniques that people use to get through the night. Some people, and I fall into this category, will urinate when they wake up. I wake up fairly frequently. So for me, this works but it might not work for somebody who's a heavy sleeper. Some people set an alarm clock or multiple alarm clocks because that works well for them. Some people wear guards or pads and other people put down a mattress pads and kind of work with the problem as it arises. There may be some continence issues that can be taken care of with pelvic floor exercises that we talked about earlier, which is the kegel exercise.

The Neobladder "On the Road, Again"

Continence is a continuum

- May need to adjust timing of fluid intake and taper or stop during evening
  - Caffeine and alcohol may impact output and continence
- Night-time tips
  - Urinate if you wake up
  - Alarm clock
  - Pads/guards
  - Mattress pads
- Long-term trend toward less continence with aging but age may not drive results
  - Pelvic health may vary over time
  - Pelvic floor exercises may help

For many of us, it's a good idea for traveling to have a MedicAlert or some kind of bracelet or dog tag so if we were unconscious that there would be some indication that we have a neobladder and they would know who to contact.

I would point out if you do any international travel that you should not put an 800 number, because they do not work outside the US. And the information should include a phone number for your neobladder urologist and indicate that there is a neobladder and any catheterization instructions and the size of the catheter needs to be a little bit different to make sure you don't get any mucus plugs, and obviously there needs to be some saline irrigation that we talked about earlier.

The Neobladder "On the Road, Again"

Medic Alert, bracelet with microchip, dog tags

- International phone number, not 800 number (Medic Alert)
- Urologist phone number
- Indicate "neobladder" and catherization instructions, if any

"Emergency Kit"

- Catheter and lubricant
- Saline
  - Note: saline is a **medical liquid** from an airport security perspective
- Spare underwear and guards/pads
- Antibiotics if prone to UTI's

Plan ahead

- Rush hour, snow/weather, meetings

NOTE: Risk of neobladder bursting is very low.

When you're away from home, whether you're traveling or at work, you may want to think about, an emergency kit. You may want to have a catheter and some lubricant with you and some saline in case you need to irrigate and remove a mucus plug.

I would point out that saline is a medical liquid from an airport security perspective. So you can get through the security lines with saline. Just point out to them if you use it for medical purposes, I have never had a problem with that. You may want to bring some spare underwear, or guards and pads, if

you run into continence issues. And if you are prone to urinary tract infections, and some of us are, you may want to bring some antibiotics along with you.

Rick Bangs:

It's a fair amount of discipline and planning I would suggest is necessary with a neobladder because we end up with this timed voiding. So let's say it's roughly four hours, give or take. And so if you're going to be driving through rush hour, or there's snow or weather conditions or meetings, or whatever you may want to void earlier than you feel like you would need to, in order to get through whatever this potential obstacle to your being able to void might be. I do want to point out that there is a very low risk of a neobladder bursting, but it is a possibility. So that's important to just keep in mind and make sure that you're voiding frequently. All right, we talked a little bit about urinary tract infections.

Tune-ups and Inspections

- Urinary Tract Infections (UTI's)
  - Will test positive for UTI's (white cells, red cells, and bacteria)
  - Report fever, flank pain, foul-smelling urine
- B12 test annually (special order)
- CO2/bicarbonate at every visit (basic metabolic panel)
- Bone density scans if at risk for osteoporosis
- Neobladder stones (more likely if incomplete emptying)

And so those of us with a neobladder are going to test positive for urinary tract infections. Remember the neobladder is made from your small intestine. So as a result, you're going to test positive for urinary tract infections, even if you don't have one. And the things that you need to watch for that would be indicators of a urinary tract infection. Because remember, we can't count on the test being accurate, things like fever and flank pain and foul smelling urine are indicators of a urinary tract infection. On an annual basis you should have a B12 test that is a test that has to be specially ordered because part of your small intestine has been removed. And so there's less absorption of B12.

That should be tested on an annual basis. It's a simple part of your blood work, but the doctor does have to order that one. There's your carbon dioxide and bicarbonate would need to be tested on a regular basis when you go to either your primary care or your urologist, but that is part of the basic kind of testing that they would do anyway. So that one does not need to be specially ordered. If you're at risk for osteoporosis you may want to get bone density scans. And there is the possibility, some people do get neobladder stones, so stones in the neobladder and that's going to be more likely if there's incomplete voiding.

And as we mentioned earlier, hydration's important from a mucus plug perspective and also from a neobladder stone perspective. Okay from an ongoing care perspective, it's probably best to go back to the surgeon that you went to, who is a specialist in neobladders, that's why you went to the surgeon. If that's not possible, and it may not be, you will find somebody who's comfortable contacting your surgical team. And you can find local urologists that are willing to work with your surgical team. The general knowledge about neobladders is fairly limited. I think Dr. Daneshmand has already come out and said that not just suggested it, but basically said that.

Rick Bangs:

So even among the specialists, there's less expertise out there than you might want. And it's obviously a good idea to have a little bit of education yourself and include the surgical team when there's an emergency related to your neobladder. Generally there are no special needs if you're having surgery or a procedure. So there would be two exceptions that we want to point out to you. The first is, and we talked about this a couple of times already is that the catheter size needs to be a little larger, so the mucus could flow and there needs to be some irrigation of the mucus as well.

Tune-ups and Inspections

Ongoing care

- If possible, return to surgeon for follow up.
- If not possible, find knowledgeable urologist comfortable contacting your surgical team.
  - In the general medical community, knowledge of neobladders and how they function is limited.
  - Prepare to educate and always include your surgical team when there is an emergency related to your neobladder.
- Generally, no special needs for surgeries or procedures
  - Catheter size is exception as they can plug with mucus (needs to be larger size than standard)
  - Need to avoid some very unusual chemotherapies that are processed via urinary tract

Rick Bangs:

And the second thing, and this would be extremely unusual, but there are some unusual chemotherapies that are processed through the urinary tract. And those should be avoided, but they are very unusual. And just if you have any questions on that, by all means, check with your doctor.

BCAN would like to thank our Patient Insight Webinar sponsors

for their support.