

# BCAN Fall Series: Survivorship

## The New Normal after Bladder Removal and Urinary Diversion

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# Disclosure

- None
- BCAN Volunteer
  - Organized the Bladder Cancer Awareness Day August 2010 at MSKCC
  - Organized the NYC Team for the BCAN Walk May 2011, May 2012 and May 2013.
  - Presently getting ready for May 3, 2014.

# Ambulatory Bladder Cancer Clinic

- The role of the Certified Wound, Ostomy, Continence Nurse – CWOCN
- Pre operative teaching and Stoma Site Marking
- Assistance with understanding and selecting a type of urinary diversion
- Post operative and ongoing consults with patients to help them with the adjustment to the new normal
- Joined the Bladder Cancer Support Group – facilitated by Richard Glassman LSW and Theo Berger RN. First heard the term the “New Normal”
- Developed an online virtual support group

# Screen Shot From the Virtual Online Bladder Cancer Support Group

**Dummy Meeting | ID: 411830 | Cisco Unified MeetingPlace**

Meeting View Layouts Tools Help

**Participant List (3)**

My Status

Speaking:  
Jamie Silverstein

Jamie Silverstein  
Richard Glassman  
Vashti Livingston

**Bladder Cancer 06-28-12.ppt**

## Bladder Cancer The Challenges Ahead

June 28, 2012

Themes include:

- Changes in physical functioning/appearance
- Medical and rehabilitation concerns
- Sexuality and intimacy
- Choosing treatment-where possible
- Managing at home
- Coping mechanisms
- Anxiety and depression
- Survivorship

Discussants include Richard Glassman, LCSW  
Vashti Livingston, RN, CWOCN and Theo Berger, RN  
technical issues: email [virtualgroups@mskcc.org](mailto:virtualgroups@mskcc.org)

**Chat**

**Jamie Silverstein:** technical issues: email [virtualgroups@mskcc.org](mailto:virtualgroups@mskcc.org)  
You will need to be on the phone in order to hear the audio for the meeting. If you need to connect by phone, click the yellow phone icon on the top right of your screen. Click "Connect Me" and enter your phone #. The system will call you back. If that does not work, email [virtualgroups@mskcc.org](mailto:virtualgroups@mskcc.org)

To: Everyone

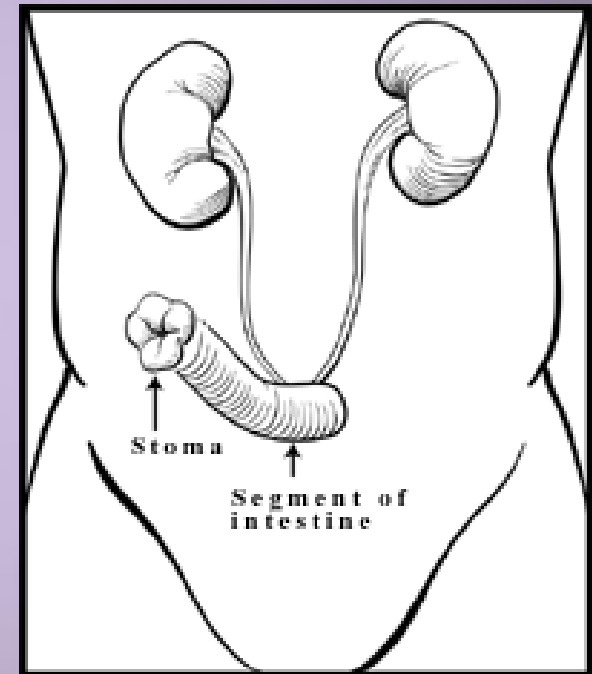
Share Stop Sharing Full screen Sync

Share Whiteboard Open Polls Wrap Up

Cisco Unified MeetingPlace Adobe Technologies

# About Urostomy/Ileal Conduit

- A **Urostomy/Ileal Conduit** provides a way for urine to be stored externally.
  - A small portion of the ileum (the last segment of the small intestine) is disconnected. One side of the piece of ileum is attached to a skin opening on the right side and a **stoma** is created.
  - A **Urostomy pouch** is placed over the stoma to collect urine.



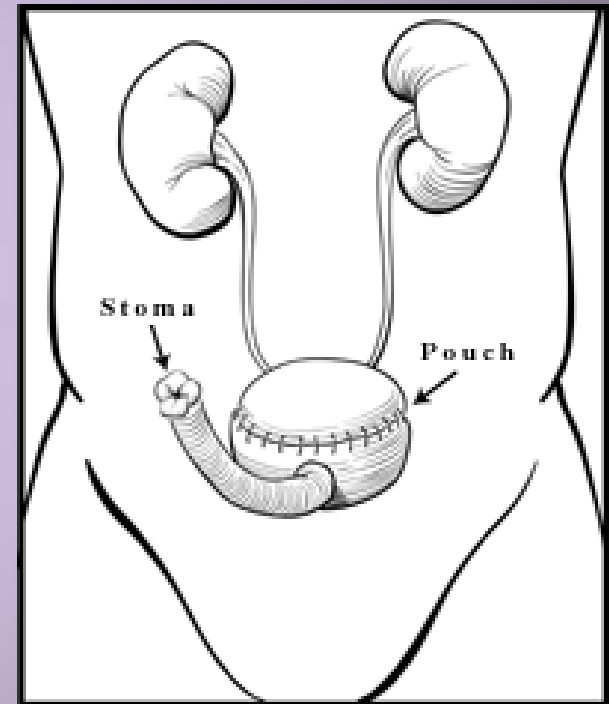
Always carry a spare urostomy pouch at all times.

# What is Normal with a Urostomy/Ileal conduit?

- The urine contains mucus
- The stoma is red and moist and shrinks over 8 weeks, has no feelings, may bleed a little during a change.
- Encouraged to drink water daily
- The type of pouching system will vary from the hospital, in the first few weeks and then afterwards as the stoma stabilizes. Sample different pouching systems. Protect the skin.
- Empty the pouch when ½ full and use a night drainage bag or bottle –leg bag is optional. Change the entire appliance every 3-5 days
- Can shower, swim, exercise and sports, travel, concealment and intimacy ([www.ostomysecrets.com](http://www.ostomysecrets.com) ; [www.stealthbelt.com](http://www.stealthbelt.com) ; [www.cmostomysupply.com](http://www.cmostomysupply.com))
- **Must walk with supplies at all times**
- Order supplies from major distributors
- Covered by most insurance (Ostomy Bill NYS see [www.uoaa.org](http://www.uoaa.org))
- If possible follow up with a local CWOCN – [www.wocn.org](http://www.wocn.org) and local ostomy association [www.uoaa.org](http://www.uoaa.org) ; online [www.bcan.org](http://www.bcan.org) and [www.C3Life.com](http://www.C3Life.com)

# About Continent Cutaneous Diversion or Indiana Pouch

- A **continent cutaneous diversion**, or **Indiana Pouch**, is an internal storage “container” for urine.
  - Using a combination of small and large intestine, a pouch is created. It is connected to the skin on the abdomen by a small stoma creating a continent urinary reservoir; no external bag is needed.
  - Several times a day, usually every four to six hours, a catheter must be passed through the stoma and into the pouch to empty the urine. Catheters should be discarded after use.



Carry several clean catheters with you at all times. A Medialert bracelet/necklace is highly recommended.

# What is Normal with an Indiana pouch/Continent Diversion

- There is mucus in the urine
- Encouraged to drink water daily
- Catheterization is necessary for emptying – initially every 2 hours and the goal is to get to about every 4- 6 hours daily so an alarm is essential at night.
- Decreased risk of leakage but we recommend use of a stoma cap or bandaid over the stoma
- Always walk with several catheters for the day, dispose of after use (in an emergency may wash with warm water and soap and reuse)
- Order catheters from major distributors and try samples – know your catheter size. (have 1 a size smaller in case of an emergency)
- Medialert bracelet or necklace is advised.

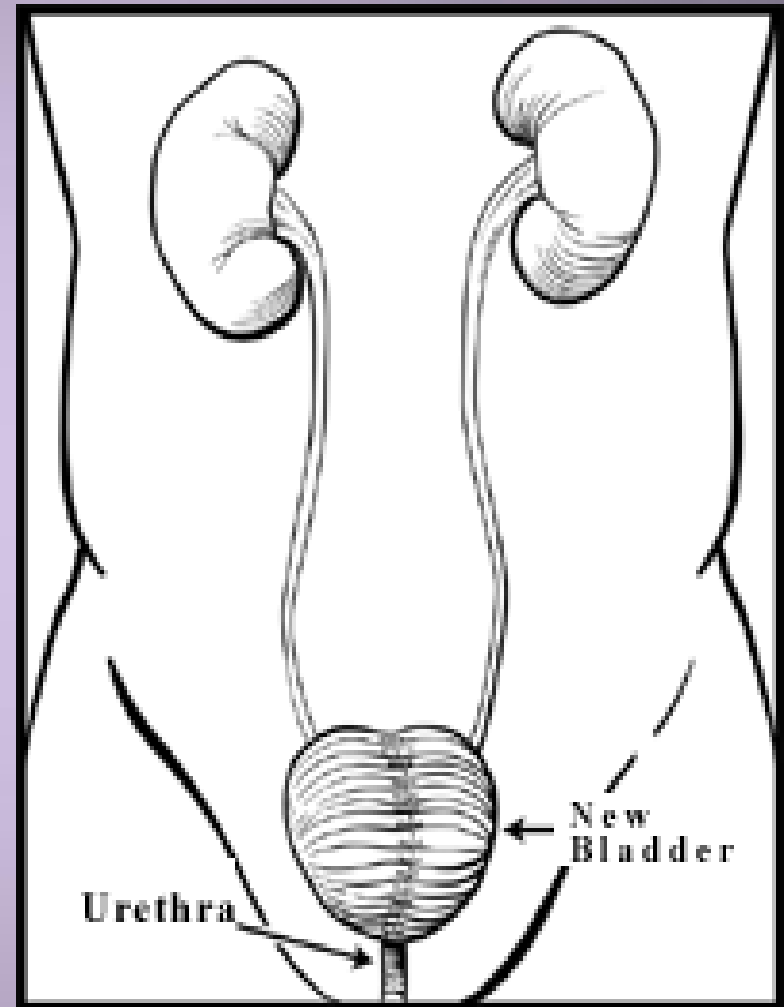


# Neobladder

A **neobladder** creates an internal storage “container” for urine.

Using a portion of small intestine, the urologist reconstructs the reservoir, while the ureters and urethra are connected to the “new bladder”

Void at regular intervals by tensing the abdominal muscles, relaxing the sphincter muscle urine can be passed out through the urethra (set an alarm at night)



Pelvic floor muscle/ Kegel exercises are recommended daily: [www.NAFC.com](http://www.NAFC.com)

# What is Normal with a Neobladder

- There is mucus in the urine.
- Encouraged to drink water
- In the early stages there will be incontinence
- Day time continence may be achieved by 2-6 months. Nighttime incontinence may persist up to 1 year.
- Combinations of adult diapers and incontinence pads are worn as needed.
- Initially voiding is done seated(**even by men**) for 5 - 10 mins, eventually the men may progress to standing during the day (we encourage 1-2 seated voids per day)
- Limit caffeine and fluids 3 hours prior to bedtime and plan to wake up at least once during the night (avoid going more than 6 hours without voiding) Use an alarm
- Kegel/pelvic floor muscle exercises are recommended daily  
[www.NAFC.org](http://www.NAFC.org)

# The New Normal

- Sexuality and Intimacy

- Men

- Removal of the bladder and prostate (radical or nerve-sparing)
    - Erectile dysfunction initially treated with vasodilators ; consult with sexual rehabilitation clinic, medication adjustment and maybe use of injections. Penile implants.
    - Some penile discharge in the early post operative period (Ileal conduit and Indiana Pouch), may have an odor, light pads are recommended – subsides in a few weeks

- Women

- Removal of the bladder, total hysterectomy (uterus, cervix, ovaries, fallopian tubes), and the upper portion of the vagina (urethra if needed)
    - Painful intercourse so instructed to use lubricants and positions that limit penetration, consult with sexual medicine service (psychologist)
    - Vaginal discharge in the early post operative period, may have an odor, pantishields are recommended may last a few months.

[www.meetanostomate.org](http://www.meetanostomate.org) ( for support, friends, relationships)

# The New Normal

- Fatigue level, exercise, driving
- Diet and bowel habits
- Signs & Symptoms of infection
  - Fever, chills, malaise, odor, discomfort, flank pain
- Work, social events, travel(TSA card)
- Resources
  - Support groups, peer to peer, online forums

# New York City Team

