SHOULD I HAVE A STOMA OR AN INTERNAL RESERVOIR WHEN REMOVING MY BLADDER CANCER?

A Decision Aid For Patients Undergoing Bladder Removal (Radical Cystectomy)

This decision aid is for you if:

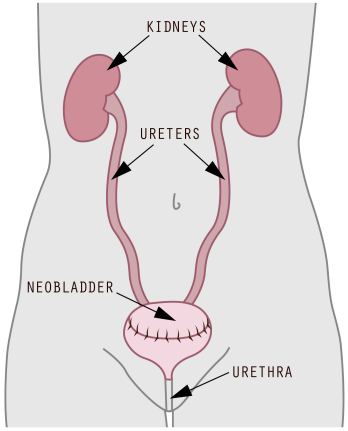
- Your bladder cancer is treatable by surgery.
- Your surgeon has told you that you require complete bladder removal for bladder cancer.

What is bladder cancer?

- Bladder cancer is an abnormal growth (tumour) located within the lining of the urinary bladder.
- When the cancer acts aggressively, it can grow into the outer muscle layer of the bladder or come back after treatment.
- If the tumour involves the muscle layer of the bladder or returns after treatment, removal of the bladder may be recommended by your surgeon.
- The most important goal of surgical treatment is to remove the entire bladder and tumour within it.
- Another important goal of surgical treatment is to create a new way for the urine your kidneys make to leave the body. This is called diversion of urine. Urine contains toxins the kidneys filter from blood, so must leave the body in order for you to live.
- There are 2 main options for diversion of urine after bladder removal. These are described in this decision aid.

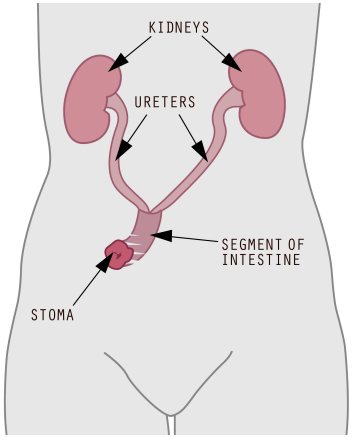
What are your options for diverting urine?

Two main options to divert urine after the bladder is removed are:



INTERNAL BLADDER REPLACEMENT (Neobladder):

- The bladder is removed and a long (40 - 60 cm) piece of intestine is used to create a substitute bladder.
- The ureters (tubes that connect kidney to bladder) are connected to one end of the substitute bladder and the other end is brought down and connected to the urethra (tube you urinate through).
- You will pass urine from the urethra, though it may take some time to learn to pass urine this way and to gain control of your urine.

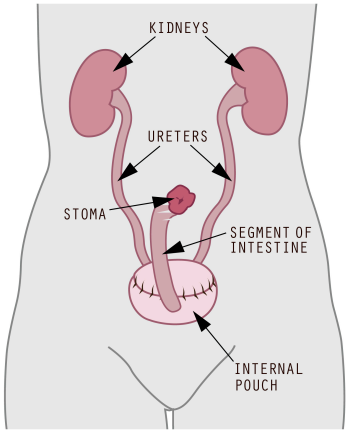


ABDOMINAL STOMA (Ileal Conduit):

- The bladder is removed and a short (15-20 cm) piece of intestine is used to create a stoma to carry urine out of the body.
- The ureters (tubes that connect kidney to bladder) are connected to one end of the piece of intestine and the other end is brought to the skin to create an opening (stoma) near the belt line.
- Your urine will continuously flow out of the stoma and into a bag which is attached to your skin and under your clothes. The bag will need to be emptied regularly.

What are other options for diverting urine?

Another option is available in some cases. Not all surgeons are experienced with this type of diversion and not all patients are good candidates for this option.



ABDOMINAL STOMA WITH INTERNAL POUCH (Continent Cutaneous Diversion):

- The bladder is removed and a long (40 - 60 cm) piece of intestine is used to create an internal pouch.
- The ureters are connected to the new internal pouch and the other end is made into a tube and brought to the skin to make a stoma.
- You will pass urine by inserting a catheter into the opening on your abdomen (stoma) to drain the pouch.

This option for urinary diversion is not discussed further in this decision aid. Your surgeon can discuss this option with you further if you meet the criteria for this procedure.

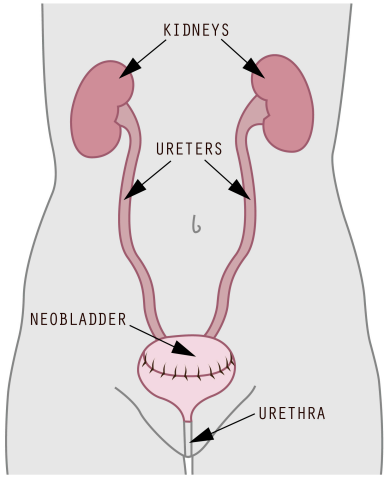
Rarely, a surgeon finds information about the cancer or your anatomy during the operation that changes the options available for urinary diversion. If this occurs, the surgeon may be limited in their options to divert the urine and must choose the best option during the operation.

What health factors may affect your options? Please circle all that apply.

Do you have…	Yes or No		Comment
Crohn's disease or Ulcerative colitis?	Yes	No	
Renal failure / Kidney disease?	Yes	No	
Liver failure / Liver disease?	Yes	No	
Major heart or lung disease?	Yes	No	
Poor control of your urine (incontinence)?	Yes	No	
Over the age of 80 years?	Yes	No	
Previous radiation treatment?	Yes	No	
Trouble getting to the bathroom on your own?	Yes	No	
Difficulty using your hands for buttons or zippers?	Yes	No	
Need a wheelchair to get around at home?	Yes	No	
Difficulty reaching or seeing your genitals?	Yes	No	

Other comments related to your health:

What are the benefits of each option for diversion?

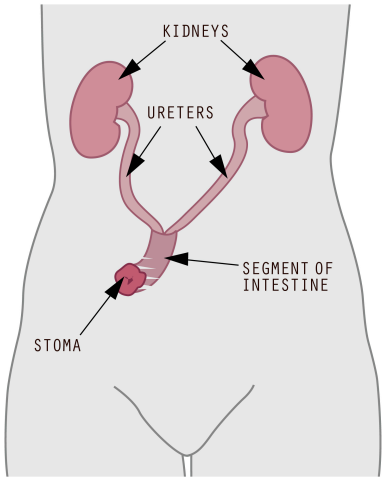


By choosing an **INTERNAL BLADDER REPLACEMENT**, you can:

- Avoid a stoma
- Pass urine similar to the way you are used to (through your urethra)[6].

You can also avoid the complications associated with a stoma including[1]:

- Intestine bulging around the stoma (hernia)
- Tightness of the opening of the stoma (stenosis)
- Skin irritation around the stoma
- Need for stoma appliances to collect urine
- Paying for medical supplies (bags, creams) needed for stoma care



By choosing an **ABDOMINAL STOMA**, you can expect:

- A shorter time in the operating room
- Urine collection into a bag around the stoma

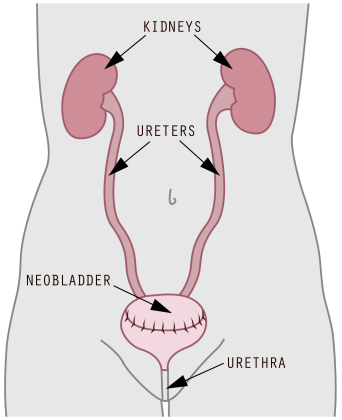
You can also avoid the complications associated with an internal bladder replacement including:

- No leaking of urine from urethra (incontinence)
- No need for catheter insertion required if you can't empty an internal bladder replacement
- Paying for pads to protect underwear from urine leakage (incontinence)
- No need to wake-up overnight to urinate

What are the possible disadvantages of each option for diversion of urine?

Blocks of 100 faces show an estimate of what happens to **100 people** after surgery to remove their bladder and divert urine. Each face represents one person and the shaded area shows the number of people affected based on current studies. It is impossible to know in advance whether you will be one of those affected. These rates are estimates based on the studies that are currently available.

INTERNAL BLADDER REPLACEMENT (NEOBLADDER)



Daytime Urinary Leakage

Up to 10% of men and 20% of women will experience *daytime urinary leakage* with **INTERNAL BLADDER REPLACEMENT** lasting more than 1 year. This may require multiple pads per day or further surgery to attempt to correct[2,3].

Men Women

Unable to Urinate

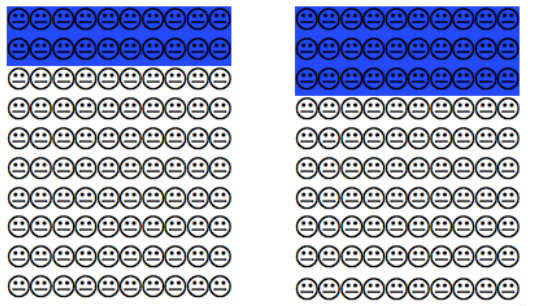
Up to 15% of men and 30% of women may be *unable to urinate* with **INTERNAL BLADDER REPLACEMENT** and require catheterization multiple times per day[2,3].

Men Women

Nighttime Urinary Leakage

Up to 20% of men and 30% of women will experience *nighttime urinary leakage* with **INTERNAL BLADDER REPLACEMENT** lasting more than 1 year[2,3]. This may require pads, nightly catheter insertion, or further surgery to attempt to correct.

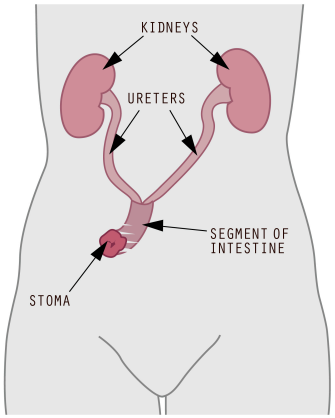
Men Women



What are the possible disadvantages of each option for diversion?

Blocks of 100 faces show an estimate of what happens to **100 people** after surgery to remove their bladder and divert urine. Each face represents one person and the shaded area shows the number of people affected based on current statistics. It is impossible to know in advance whether you will be one of those affected. These rates are estimates based on the studies that are currently available.

ABDOMINAL STOMA (ILEAL CONDUIT)



Hernia around Stoma

Up to 15% of patients (both men and women) may form a hernia (intestine protrusion) around the stoma site. This can be visually unappealing and sometimes painful. It may require further surgery to correct[1,3].

Tightness of Stoma

Up to 3% of patients (both men and women) may develop tightness (stenosis) at the opening of the stoma site. This may need to be stretched open or, in some cases, require further surgery[1].

What matters most to you?

Some common reasons to choose each option are listed below. Please mark with ☑ how much each reason matters to you on a scale of **1 to 5**.

"1" means it is **not important** to you**. "5"** means it is **very important** to you.

Reasons to choose an INTERNAL BLADDER REPLACEMENT

How important is it for you to urinate similar to the way you are used to?	1 2 3 4 5
How important is it for you to avoid caring for a stoma?	1 2 3 4 5
How important is it for you to avoid the complications associated with a stoma (hernia, tightness of the opening)?	1 2 3 4 5

Reasons to choose an ABDOMINAL STOMA

How important is it for you to avoid a long operation?	1 2 3 4 5
How important is it for you to avoid needing to catheterize?	1 2 3 4 5
How important is it for you to avoid leaking urine (incontinence)?	1 2 3 4 5

Considering the options and what reasons are important to you, which option do you prefer?

Please check ☑ one:

- ☐ Internal Bladder Replacement (Neobladder)
- ☐ Abdominal Stoma (Ileal Conduit)
- ☐ I'm not sure yet

Knowledge Check

How well did this decision aid help you learn the key facts about each type of diversion?

Please check ☑ the best answer:

	TRUE	FALSE	NOT SURE
1. An abdominal stoma (ileal conduit) will require a stoma bag to collect urine.	☐	☐	☐
2. An internal bladder replacement (neobladder) will require a longer operation.	☐	☐	☐
3. Urine leakage in the daytime is worse than nighttime with an internal bladder replacement (neobladder).	☐	☐	☐
4. A hernia around a stoma will always heal on its own.	☐	☐	☐

Check your answers on the bottom of the next page.

Find out how comfortable you feel about deciding

	YES	NO
Do you know enough about the risks and benefits of each option?	☐	☐
Are you clear on which benefits and side effects matter most to you?	☐	☐
Do you have enough support and advice from others (surgeon, family) to make a decision?	☐	☐
Do you feel sure about the best choice for you?	☐	☐

If you answered 'No' to any of these, discuss with your doctor or seek another doctor's opinion (The SURE Test © O'Connor & Légaré, 2008)

What are your next steps?

Please check ☑ one:

- ☐ I am ready to discuss my decision with my surgeon
- ☐ I need to discuss the options with my family and my surgeon in further detail
- ☐ I need to read more about the options

Answers to knowledge check: 1. True 2. True 3. False 4. False

Disclaimer: The information included in this decision aid is not intended to replace the advice of a healthcare provider. Certain situations will necessitate an intraoperative decision to choose one diversion over another. Your surgeon can go into more detail regarding this.

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The level of evidence for studies referenced in this decision aid varied. Although systematic reviews and meta-analyses were included for many of the outcomes, some outcomes were obtained from cohort studies.

SMOG Readability Factor: 6.6 (Seventh Grade)

References:

1) Olsson CA. Stoma and anastomotic complications of ileal conduit diversion. *J Urol.*2007;178(3):755.
2) Lee RK, Abol-Enein H, Artibani W, et al. Urinary diversion after radical cystectomy for bladder cancer: options, patient selection and outcomes. *BJU Int.* 2014;113:11-23.
3) Hautmann RE, Abol-Enein H, Hazez K et al. World Health Organization consensus conference on bladder urinary diversion.*Urology*.2007;69:17-49.
4) Smith AB, Crowell K, Woods ME et al. Functional outcomes following radical cystectomy in women with bladder cancer: A systematic review. *Eur Urol Focus.*2017;3(1):136-143.
5) Kulkarni JN, Pramesh CS, Rathi S et al. Long-term results of orthotopic reconstruction after radical cystectomy. *BJU Int.*2003;91:485-488.
6) Yang LS, Shan BL, Shan LL et al. A systematic review and meta-analysis of quality of life outcomes after radical cystectomy for bladder cancer. *Surg Onc.*2016;25(3):281-97.