

Cystectomy and Childhood Cancer

The information in this Health Link will help you recognize signs and symptoms of urinary bladder problems that may occur after cystectomy.

What is a cystectomy?

A **cystectomy** is an operation to remove the urinary bladder.

Who needs a cystectomy?

Two groups of cancer survivors may have undergone a cystectomy during their childhood cancer treatment. The first group includes those who had a **cystectomy as part of their cancer treatment**. Successful treatment of rhabdomyosarcoma of the urinary bladder and prostate, Ewing's sarcoma, and other sarcomas in the pelvic area sometimes requires cystectomy. The second group includes people who required a **cystectomy because of treatment complications**, such as hemorrhagic cystitis (bleeding) or bladder fibrosis (scar tissue).

How does urine exit the body after a cystectomy?

After the urinary bladder is removed, a new passageway is created so that urine can leave the body. Urine is removed from the kidney in a process called "**diversion**". There are three main types of diversions, based on whether urine flows from the body spontaneously ("**incontinent diversion**") or is collected in a reservoir ("**continent diversion**").

An "**incontinent diversion**" is usually made through a loop of small intestine that is separated from the rest of the bowel and called an "**ileal conduit**" or "**urostomy**". The ileal conduit is connected to the outside of the abdomen by way of an opening called a "stoma". Internally, the ureters empty into the conduit, which then serves as a pipeline for urine to flow directly through the stoma.

There are two types of "**continent diversions**." The first is the **cutaneous continent diversion**. This reservoir is made from intestine and is placed within the abdomen in front of the kidneys. The ureters are then connected to this pouch. The appendix or another short piece of small intestine is used to create an extension from this pouch through the abdominal wall to the surface of the skin, often around the belly button. This opening is called a "stoma". This design prevents urine from flowing back into the kidney (reflux) or spilling out onto the skin. Urine collects in the reservoir, and is removed several times a day by insertion of a catheter (tube) into the stoma.

The second type of continent diversion is done by making a new bladder from bowel and is called an "**orthotopic neobladder**". The neobladder is connected directly to the urethra. Some people with a neobladder are able to urinate naturally, while others may require catheterization to empty the bladder.

What problems can occur following cystectomy?

People who have an ileal conduit or ileal pouch may have **leakage of urine** around the stoma. This may lead to **irritation of the skin** and **infection** at the site of the stoma. Scar tissue ("**strictures**") may form around the ureters or the conduit and block the flow of urine from the kidneys. **Reflux** of urine into the kidney may also occur, which increases the risk of a UTI or kidney stones.

Incontinence, or the inability to control passage of urine, may occur after a neobladder is formed. People with this problem may benefit from muscle re-training in order to control urination effectively. If there is persistent leakage of urine, pressure testing of the neobladder and urethra may help decide about treatment.

Bladder surgeries involving portions of the small intestine sometimes causes abnormal levels of chemicals and fats in the blood. These problems may result in **diarrhea**, **kidney stones**, and/or low levels of **Vitamin B12**.

Cystectomy may also increase the risk of **sexual dysfunction** in both men and women. Surgery and medications may be used to treat this complication.

What can I do if I have a problem following cystectomy?

If you have had a cystectomy, you will need life-long **close follow-up by a urologist**. An enterostomal nurse ("ET nurse") can help by giving advice about skin care, appliance fitting, and supplies. The nurse can also help "troubleshoot" if there are problems with catheterization.

What monitoring is recommended?

If you had an ileal enterocystoplasty (bladder surgery involving a portion of the small intestine), you should have a yearly blood test to check your Vitamin B12 level starting 5 years after your bladder surgery.

When should I call my healthcare provider?

Call your healthcare provider whenever you have **fever, pain in the midback or side, blood in the urine, or severe irritation of the skin**. If you perform self-catheterization and have **difficulty inserting the catheter**, this is a **medical emergency** that needs immediate attention. This complication may mean that the pouch has ruptured, or that the pouch will rupture if the reservoir cannot be drained properly. This can result in serious infection from leakage of urine into the abdomen or pelvis. **If you have had a cystectomy, contact your healthcare provider immediately if you have vomiting or abdominal pain**. These symptoms may indicate a bowel blockage (obstruction) from scar tissue.

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Additional health information for childhood cancer survivors is available at
www.survivorshipguidelines.org

Note: Throughout this *Health Links* series, the term "childhood cancer" is used to designate pediatric cancers that may occur during childhood, adolescence, or young adulthood. *Health Links* are designed to provide health information for survivors of pediatric cancer, regardless of whether the cancer occurred during childhood, adolescence, or young adulthood.

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