WE ARE THE SHARPEST TOOL IN YOUR SHED.

**Bladder Cancer Basics for the Newly Diagnosed**
From diagnostics to treatment options, this easy-to-read handbook answers many questions and provides a roadmap to treatment.

**Conversations: Let's Talk About Bladder Cancer**
This video series poses the questions that patients or caregivers may be reluctant to ask doctors.

**Survivor 2 Survivor**
This program connects newly diagnosed patients with survivors who have undergone similar treatment. The volunteers provide their firsthand account of life with a bladder cancer diagnosis.

**Patient Insight Webinar Series**
Led by experts in the field, the series explores bladder cancer topics in depth and features audience Q&A.

**“The New Normal” Video Series**
Eight bladder cancer survivors discuss life after urinary diversion and provide tips for those facing bladder removal surgery.

**BCAN Connection**
This information and referral line is staffed by BCAN volunteers that provide practical resources to assist bladder cancer patients and their loved ones.

The Bladder Cancer Advocacy Network is the only organization dedicated to increasing public awareness, advancing research, and providing education and support to those living with the disease. Find Answers, Advance Research, and Get Involved at [www.bcan.org](http://www.bcan.org) or call 1-888-901-BCAN (2226).
More than 500,000 bladder cancer survivors are currently living in the United States, and an estimated 74,000 new cases of bladder cancer are expected to be diagnosed in 2015. As with many cancers, early detection improves the likelihood of successful treatment. Early symptoms of bladder cancer often involve urinary symptoms, but unfortunately, many of those symptoms are often thought to be caused by a common condition, such as a urinary tract infection. Blood in the urine may be an early indication of cancer, and other symptoms include the need to urinate more frequently and a painful and/or burning sensation during urination.

THE BLADDER
The bladder is a hollow organ located in the pelvis that functions as part of the urinary system (Figure 1). Its primary purpose is to store urine before it is eliminated from the body. Urine travels to the bladder from the kidneys through tubes called ureters. The bladder wall is comprised of four layers: the urothelium, lamina propria, muscularis propria, and serosa.

The urothelium, also called the transitional epithelium or mucosa, is the innermost layer of the bladder and is composed of cells called urothelial or transitional cells. The next layer, the lamina propria, is composed of thin connective tissue, blood vessels, and nerves. The muscularis propria is thick muscle that makes up the third layer. Lastly, the outermost layer, the serosa, is made up of fatty connective tissue that helps separate the bladder from nearby organs. Together, all of the layers make up a flexible bladder wall.

The bladder can hold approximately two cups of urine. When it is full, the urge to urinate occurs. When you are ready to urinate, the muscles in the bladder wall contract and force the urine out of the body through a tube called the urethra.

TYPES OF BLADDER CANCER
Most bladder cancers start in the cells that line the surface of the bladder that's in contact with urine. The most common type of bladder cancer is transitional cell carcinoma—also called urothelial cell carcinoma—and it is divided into two subtypes: papillary and sessile or flat. Papillary tumors grow from the inner lining of the bladder toward the center of the bladder, while sessile tumors grow along the surface of the lining. Both of these types of tumors can be classified as invasive, which are tumors that have grown deep into the bladder wall, or noninvasive, which are tumors that have not penetrated any other layers of the bladder. Other types of bladder cancer include squamous cell carcinoma, adenocarcinoma, and small cell carcinoma—all three may be invasive. These subtypes may also be present in one tumor, which can make accurate diagnosis difficult.

RISK FACTORS
When most people receive a diagnosis of any type of cancer, they want to know what may have caused the disease. Bladder cancer most frequently develops in people who are 55 years or older; the average age at the time of a bladder cancer diagnosis is 73 years. Bladder cancer occurs three to four times more often in men than women and is more common in white individuals compared with black individuals. The precise cause of bladder cancer remains unknown, but risk factors linked to the disease include smoking, exposure to certain chemicals (particularly those encountered through work in the chemical industry), diesel exhaust, environmental pollutants, chronic bladder infections, a family history of bladder cancer, previous radiation to the pelvis, or prior use of the chemotherapy drug cyclophosphamide (Cytoxan). It's important to remember that many people diagnosed with bladder cancer don't have any of these risk factors, and the disease never develops in many people who do have one or more of these risk factors.

BLADDER CANCER AT TIME OF DIAGNOSIS

- Bladder cancer is contained to originating cells.
- Bladder cancer is deeper but still confined to the bladder.
- Bladder cancer has spread to nearby tissues outside the bladder.
- Bladder cancer is metastatic.

ADDITIONAL RESOURCES
- American Bladder Cancer Society: www.bladdercancersupport.org
- American Cancer Society: www.cancer.org
- Bladder Cancer Advocacy Network: www.bcan.org
Ways to diagnose bladder cancer

At the first sign of bladder cancer, doctors recommend additional testing to better define the disease and evaluate how advanced it is. Your doctor will have performed a thorough physical exam as part of your diagnostic testing, which likely included questions about your personal medical history, your family history of disease and any risk factors you might have.

The most common tests done to diagnose bladder cancer include cystoscopy, cytology and the imaging of kidneys and ureters. Following is a brief description of each of these tests as well as others your doctor may prescribe.

URINE TESTS

- **Cytology** – a sample of urine is examined under a microscope to see if it contains any cancer cells.
- **Culture** – a sample of urine is placed into a dish in the laboratory to see if bacteria grow. This test is done to determine whether an infection – rather than cancer – may be causing your symptoms.
- **Tumor marker testing** – a urine sample is tested for specific substances commonly released by bladder cancer cells.
- **Molecular marker testing** – a urine sample is tested for genetic abnormalities that have been shown to be associated with bladder cancer.

IMAGING STUDIES

- **Computed tomography (CT)** – a test in which a scanner creates X-ray images of organs, tissues and bones inside the body and displays them on a computer screen. You will need to lie still on a table while the scan is being done. A special dye, called a contrast medium, may be injected into a vein in the arm, or you may be asked to drink a contrast liquid before the scan; this contrast enhances the images to provide better details. CT may also be called CAT.
- **Computerized tomography (CT) urogram** – A CT urogram is a type of CT scan used to create images of the bladder, kidneys and ureters. As the contrast medium flows through these areas, X-ray pictures are taken to help assess how well the urinary tract is functioning and to look for abnormalities.
- **Magnetic resonance imaging (MRI)** – an imaging test that involves the use of magnetic fields instead of X-rays to visualize internal structures of the body. For an MRI scan, you will lie on a table that moves through a large circular scanner. As with CT, a contrast medium may be injected into a vein in the arm before the scan to enhance the images. An MRI is done to see if cancer cells have spread outside of the bladder.
- **Ultrasound** – a test in which sound waves are used to produce images of the organs inside the abdomen, including the bladder and nearby tissues.
- **Retrograde pyelogram** – a catheter (thin tube) is inserted into the bladder, and dye is injected to make the bladder walls and any existing tumors easier to see on an X-ray. This test is usually done during a cystoscopy.
- **Bone scan** – a test done to see if cancer has spread to your bones. A chemical called a radioactive tracer is injected into a vein in your arm and travels through your bloodstream to your bones where it collects and gives off a small amount of radiation. The radiation is then detected by a special camera that scans your body and takes pictures to show how much of the tracer has collected in your bones. This test shows “irritation” in the bone, which may – but does not always – indicate the spread of cancer to the bone.

BIOPSY PROCEDURES

- **Biopsy** – a procedure to remove a piece of tissue from a tumor or nearby tissue for examination. A pathologist analyzes the biopsy tissue sample and provides your doctor with a report of the findings, which include such details as the type and subtype of cancer, the grade, and other abnormalities. Bladder biopsy samples are almost always obtained during cystoscopy depending on how deep the cancer has spread.
- **Cystoscopy** – a procedure that allows doctors to examine a patient’s bladder by inserting a cystoscope (a thin tube with a light and camera at the end) through the urethra. Sterile salt water is injected through the cystoscope to fill and expand the bladder, so that doctors can look for abnormal growths on the lining of the bladder. To obtain a biopsy sample, a thin instrument can be inserted through the cystoscope to cut out a small piece of the abnormal tissue to be evaluated. A cystoscopy is usually performed with the use of local anesthesia, but general or spinal anesthesia may be needed for some patients.
- **CT-guided needle biopsy** – a procedure to remove a biopsy tissue sample that involves inserting a needle through the belly into the bladder tumor. CT is used to help the doctor see exactly where the tumor is located so the needle can be inserted precisely.

SURVIVOR VOICE | Mike Urbom | Bladder cancer survivor and Vietnam veteran

“When I had symptoms – and after the official diagnosis – I did a lot of self-educating. I firmly believe that you’re in charge of your own education. You have to ask the questions, look for the answers and do your research.”

ADDITIONAL RESOURCES

- American Cancer Society: [www.cancer.org](http://www.cancer.org)
- Bladder Cancer Advocacy Network: [www.bcan.org](http://www.bcan.org)
- National Cancer Institute: [www.cancer.gov](http://www.cancer.gov)
Understanding your diagnosis

Once bladder cancer is diagnosed, your doctor needs to establish if the disease has spread and if so, to what other parts of the body. Diagnostic testing helps determine how invasive the cancer is based on how far the disease has spread in and around the bladder. Bladder cancer is classified as one of the following:

- **Noninvasive** – confined to the inner layers of the bladder; noninvasive bladder cancer is also called superficial or non-muscle invasive.
- **Invasive** – the cancer has grown deep into the bladder or spread to lymph nodes or other organs.

In addition to knowing whether the cancer is noninvasive or invasive, knowing the stage and grade of bladder cancer will help you and your health care team choose the most effective treatment plan possible.

**STAGE OF DISEASE**

Bladder cancer is usually staged in two phases:

1. **Clinical stage** – based on the results of a physical examination, evaluation of biopsy specimens, and the results of imaging studies and CT scans.
2. **Pathologic stage** – based on more invasive testing, including surgery, in order to accurately establish how far the disease has spread. Assigning this stage normally includes the removal and testing of the bladder and/or nearby lymph nodes to examine the tissue. This stage is assigned by a pathologist, a specialist in determining the cause of diseases, including cancer.

**TNM system**

One of the most standard ways to classify a cancer stage is through the TNM system, which was developed by the American Joint Committee on Cancer (AJCC). Doctors take into consideration the size and location of the tumor itself (T), whether cancer cells are found in nearby lymph nodes (N) and if the cancer has metastasized, or spread, to other parts of the body (M) (Table 1).

Once the bladder cancer has been classified according to the TNM system, an overall stage will be assigned (Table 2).

**Stage 0** – Abnormal cells that may lead to cancer are present in only the innermost layer of the bladder lining. This stage has two subcategories: Stage 0a refers to noninvasive papillary carcinomas, and Stage 0is refers to flat carcinoma in situ. This is the earliest and most treatable stage of cancer.

**Stage I** – Cancer cells are confined to the bladder, but the tumor has grown through the inner layer of the bladder lining and into the connective tissue of the bladder. Stage I cancer is typically very treatable.

**Stage II** – Cancer cells are confined to the bladder, but the tumor has grown through the first two layers of the bladder lining and into the muscle layer.

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**TABLE 1**

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**TABLE 2**

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STAGES OF BLADDER CANCER

**Stage 0a**
Also known as noninvasive papillary carcinoma, abnormal cells that may lead to cancer are present in only the epithelial layer of the bladder lining.

**Stage 0is**
Also known as "carcinoma in situ" or "flat tumor," abnormal cells that may lead to cancer are present in only the epithelial layer of the bladder lining.

**Stage I**
Cancer cells are confined to the bladder, but the tumor has grown through the epithelial bladder lining and into the lamina propria (part of the subepithelial connective tissue).

**Stage II**
Cancer cells are confined to the bladder, but the tumor has grown through the first two layers of the bladder lining and into the muscularis propria (the muscle layer).

**Stage III**
The tumor has spread to the outermost layer of the bladder, or it has grown through the layer and may also have spread to the prostate in men, or to the uterus and/or vagina in women. The cancer has not yet spread to lymph nodes or other organs.

**Stage IV**
The tumor may be any size but may have spread to the pelvic or abdominal walls. Cancer cells have likely spread to one or more regional lymph nodes and may have spread to other parts of the body.

- **Stage III** – Cancer cells have spread to the outermost layer of the bladder (serosa) and may also have spread to the prostate (in men) or the uterus and/or vagina (in women). The cancer has not yet spread to the lymph nodes or other organs.
- **Stage IV** – Cancer cells have spread in one of three ways. They may have spread to the pelvic or abdominal walls but not to lymph nodes or other parts of the body. They may have spread to one or more regional lymph nodes but not to other parts of the body. Or they may have spread to other parts of the body, with or without affecting lymph nodes.

**Tumor grade**
The pathologist will also assign a grade to bladder cancer depending on how the cancer cells look under a microscope. The grades are as follows:
- **Low-grade** – also known as well-differentiated, is assigned when the cancer cells look similar to normal bladder tissue cells.
- **High-grade** – also known as poorly differentiated or undifferentiated, is assigned when the cancer cells look more abnormal; high-grade cancer is known to be more aggressive.

**ADDITIONAL RESOURCES**
- American Cancer Society: www.cancer.org/BladderCancerStaging
- American Society of Clinical Oncology: www.cancer.net/BladderCancerStagesAndGrades
- National Cancer Institute: www.cancer.gov/types/bladder
Making decisions about bladder cancer treatment can be difficult because of all the options and factors that must be considered. Talk openly with your cancer care team and ask questions about the available treatment options so you can determine the best choice for your individual diagnosis.

The most common treatments for bladder cancer include surgery, intravesical therapy, chemotherapy and radiation therapy. You may also receive palliative (supportive) therapy to relieve any symptoms and side effects you may have.

SURGERY

Many early-stage bladder cancers can be diagnosed and treated solely with transurethral surgery, also called transurethral resection (TUR) or transurethral resection of a bladder tumor (TURBT). In this procedure, a resectoscope – a thin tube with a lens and a light on one end – is inserted through the urethra into the bladder to remove the tumor. No incisions are necessary, but you will be given either general anesthesia (to put you to sleep) or a regional anesthesia (to numb your lower body). If any cancer remains after the surgery, a second treatment approach may be needed.

When bladder cancer is invasive, more extensive surgery may be needed to remove all or part of the bladder, depending on the size and location of the tumor. The procedure to remove the bladder is called a cystectomy. Removal of only a portion of the bladder is called a partial cystectomy; removal of the entire bladder is called a radical cystectomy. Surrounding lymph nodes and nearby organs, such as the prostate in men and the ovaries, fallopian tubes, uterus and vagina in women, may also be removed. Typically, cystectomy is done through a long incision in the belly, but laparoscopic surgery may be an option. Laparoscopic surgery involves several small incisions through which surgical instruments are inserted to remove the bladder and any affected organs nearby.

When the bladder is removed, a new way to store and eliminate urine is needed. Several surgical options are available, and choosing the best one will depend on your overall health and personal preference. Additional information on bladder removal and reconstruction can be found on page 8.

INTRAVESICAL THERAPY

Intravesical therapy is the administration of medication directly to the bladder through a catheter. The medication targets the urothelial cells that line the bladder wall; these medications are limited in their ability to penetrate the bladder wall, so intravesical therapy is typically only effective for early-stage, noninvasive tumors.

The two main types of medications used in intravesical treatment are immunotherapy and chemotherapy.

The immunotherapy drug, Bacillus Calmette-Guerin (BCG), is a modified tuberculous bacteria approved for the treatment of early-stage bladder cancer and as treatment to reduce the risk of recurrence in noninvasive bladder cancers, commonly after surgery to remove the tumors. Treatment through intravesical therapy with BCG has been shown to increase the chance of a complete response after surgery. When it is injected into the bladder, it causes inflammation that results in an immune response (see Figure 1). This immune response brings the body’s immune cells directly to the bladder, where they can destroy bladder cancer cells.

Intravesical chemotherapy allows chemotherapy drugs to attack the cancer without affecting other parts of the body, as is the case with standard (systemic) chemotherapy. Intravesical chemotherapy drugs commonly used to treat bladder cancer include mitomycin-C, gemcitabine (Gemzar) and valrubicin (Valstar).

CHEMOTHERAPY

Chemotherapy is the use of powerful drugs to kill cancer cells. Aside from certain chemotherapy drugs that are given intravesically, most drugs are used as systemic treatment, which means they travel throughout the body. This type of treatment may be effective for invasive tumors that have spread beyond the lining of the bladder. Chemotherapy may be given as one drug alone or as a combination of drugs, and is primarily used to treat tumors that have spread from the bladder to other organs, such as the liver or lungs. A common chemotherapy regimen for metastatic bladder cancer is a combination of four drugs known as MVAC: methotrexate (Trexall), vinblastine, doxorubicin (Adriamycin) and cisplatin (Platinol, Platinol-AQ). Another commonly prescribed chemotherapy drug used to treat bladder cancer is gemcitabine.

RADIATION THERAPY

Radiation therapy involves the use of high-energy radiation to kill cancer cells and shrink tumors. The most common type of radiation used for bladder cancer is external-
beam radiation therapy, which is radiation directed at the cancer from a machine outside the body. This type of treatment is most often used in the following circumstances:
• After surgery for early-stage bladder cancer
• Primary treatment for early-stage bladder cancer in patients who cannot have surgery
• Part of the primary treatment plan for advanced bladder cancer
• Palliative therapy to help prevent or treat advanced bladder cancer symptoms

CHEMORADIATION THERAPY
A combination of chemotherapy and radiation therapy, known as chemoradiation, may be given after the bladder tumor is removed (using TURBT), or instead of surgery. This treatment approach is considered a “bladder-preservation” option because removal of the bladder may not be necessary if no cancer is detected after treatment (see sidebar below).

CLINICAL TRIALS
Clinical trials are the controlled studies of investigational drugs or other types of treatment. In some cases, patients may want to participate in a clinical trial to gain access to certain treatments before they are officially approved. New drugs for advanced bladder cancer are showing promise in early clinical trials, so talk to your doctor about any trials that may be appropriate for your diagnosis. Knowing all of your treatment options, including trials, will help you make more informed decisions about your cancer care.

BLADDER-PRESERVATION THERAPY
Over the last 20 years, national and international clinical trials have been held to test bladder preservation in patients with invasive bladder cancer by combining surgical transurethral resection of the bladder tumor (TURBT) with external beam pelvic radiation concurrently with systemic chemotherapy (chemoradiation).

These trials, conducted by the National Cancer Institute in the United States as well as by organizations in both the United Kingdom and Europe, show this technique is well tolerated and can be an option for some people to avoid the need for bladder removal.

Patients believed to be good candidates for chemoradiation therapy include those whose tumors:
• appear to be have been completely removed by TURBT
• have invaded no deeper than the muscle wall
• have not obstructed a ureter

Prior to choosing your treatment plan for invasive bladder cancer talk to your cancer treatment team, ideally in a multidisciplinary bladder cancer specialty clinic including a radiation oncologist, a medical oncologist and a urologist about whether bladder preserving therapy is an option. Additional facts about this procedure include:
• It is well tolerated—even in the elderly
• If bladder removal is necessary for recurrence the surgical complication rates for cystectomy are similar to those without prior chemoradiation
• High survival rates from cancer are stable from 5 to 15 years
• The retained bladder functions well

If you choose this type of treatment, you will have a strict follow-up schedule to be monitored for signs of recurrence. It is important so that if your cancer does return, you can move forward with the best treatment for recurrent disease. Evidenced-based medicine now shows that TURBT plus chemoradiation can be a patient-friendly approach for the well-selected patient.

TREATING RECURRENT BLADDER CANCER
If bladder cancer returns after treatment, it is called recurrent cancer. Recurrence can happen weeks, months or even years after treatment stops, and the cancer may come back in the same area of the body as the primary cancer (local recurrence), or in a different area of the body (distant recurrence). While doctors cannot be certain about which patients will have cancer recurrence, they can often make predictions based on the recurrence patterns of some cancers. For example, when noninvasive bladder cancer recurs, it is most commonly local recurrence, in either the same site as the original tumor or elsewhere in the bladder. Treatment options for recurrent cancer depend on the location and extent of the tumor, treatment history and overall health.

ADDITIONAL RESOURCES
• American Bladder Cancer Society: www.bladdercancersupport.org
• American Cancer Society: www.cancer.org Bladder Cancer
• American Society of Clinical Oncology: www.cancer.net
• BCAN Bladder Preservation Therapy: www.bcan.org
• National Cancer Institute: www.cancer.gov Bladder Cancer Treatment (PDQ)
If you have muscle-invasive bladder cancer, superficial cancer involving a large area of the bladder, or your cancer recurred after having intravesical therapy, your care team may recommend surgical removal of the bladder (cystectomy). In most cases, the entire bladder is removed (radical cystectomy), along with nearby lymph nodes and reproductive organs.

A radical cystectomy may be performed through one incision in your belly or done with a laparoscope or robotic equipment through several smaller incisions.

RECONSTRUCTIVE SURGERY

After the bladder has been removed, the surgeon will perform reconstructive surgery to provide a new way to store and eliminate urine (a urinary diversion). The type of diversion depends on your medical condition and personal preferences. Options include the following:

- **Ileal conduit** – the surgeon removes a section of the intestine and then reconnects the rest of the intestine. One end of the removed section is connected to the ureters, which carry urine from the kidneys. The other end is attached to a surgically made opening in the belly (a stoma). Urine flows continuously through this ileal conduit to the outside, collecting in a small bag attached to the stoma (an ostomy bag) that is emptied periodically. The pouch will lie flat against the body and can be covered with your clothes. This surgery is known as an incontinence diversion because the patient no longer controls the flow of urine from the body.

- **Continent cutaneous pouch** – the surgeon uses a section of intestine to create a urine storage pouch within the body. This pouch, also referred to as an Indiana pouch, is connected to the ureters on one end and to a stoma on the other. The patient drains the pouch by inserting a catheter (small thin tube) through the stoma. This surgery is known as a continent diversion because the patient controls the flow of urine.

- **Orthotopic bladder (neobladder)** – The surgeon uses a section of intestine to create a replacement for the bladder. One end of the intestine is connected to the ureters, and the other end is connected to the urethra, the tube that normally drains urine from the body. The urge to urinate is lost with this procedure.

With an ileal conduit, stents (small mesh tubes) may be inserted through the stoma to the ureters to help drain urine while the patient heals. For a continent cutaneous pouch or neobladder, catheters and/or stents may be placed to help with drainage.

The typical stay in the hospital after surgery is about a week. During this time, you will learn how to care for your urinary diversion and for any catheters or stents that may still be in place when you go home. One of the most important things to remember is to always wash your hands with soap and water before and after caring for your urinary diversion.

LIVING WITH URINARY DIVERSION

Once at home, you will continue caring for your urinary diversion as you were taught in the hospital.

- **Ileal conduit** – the stoma and skin around it must be washed, rinsed, and dried completely each day. The plastic pouch attached to the stoma needs to be rinsed and cleaned daily and changed every five to seven days. A cover can be used over the pouch to absorb sweat and make you feel more comfortable. A valve at the bottom of the pouch is used to empty urine into the toilet. At night, a tube can be attached to the valve to carry urine to a bigger pouch while you sleep.

- **Continent cutaneous pouch** – after any stents and catheters are removed, urine can be emptied by inserting a catheter through the stoma and draining the urine into the toilet. The stoma and surrounding skin must be washed and dried before and after each catheterization. Initially, the pouch will need to be drained every two to three hours, but over time, you should be able to drain the pouch every four to six hours.

- **Neobladder** – after the catheters are removed, an incontinent pad (such as Depend) and an absorbent pad on the bed at night will be necessary until your urinary control improves. Your doctor will give you a urination schedule, which usually begins with urinating every two hours. Bearing down (the Valsalva maneuver), as if having a bowel movement will cause urination. You may be asked to insert a catheter twice a day after urinating to see if the bladder is emptying completely. The catheter must be irrigated during one of the catheterizations to remove mucus produced by the piece of intestine used to make the neobladder.

In subsequent weeks, the length of time between urinating will increase, and you will be able to catheterize and irrigate fewer times a day. Most patients have satisfactory urinary control during the day within three months, although there occasionally may be a little leakage, such as when you cough. Nighttime leakage may continue for a year or be permanent. Performing Kegel exercises will help to strengthen the sphincter muscle that holds urine in.

You probably will be able to resume normal activity four to six weeks after surgery, although recovery time varies by individual.

ADDITIONAL RESOURCES

- **American Cancer Society**: [www.cancer.org](http://www.cancer.org)
- **American Society of Clinical Oncology**: [www.cancer.net](http://www.cancer.net)
- **Bladder Cancer Advocacy Network**: [www.bcan.org](http://www.bcan.org)
- **National Cancer Institute**: [www.cancer.gov](http://www.cancer.gov)

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MANAGING SIDE EFFECTS

Here’s encouraging news about the possible side effects of bladder cancer treatment – with supportive care, you can manage or even prevent many of them.

Not everyone who is treated for bladder cancer will experience the same side effects. Whether you have a particular side effect depends on such things as your age, your overall health, your specific cancer and your treatment plan.

Side effects differ in regard to timing. Short-term side effects occur during treatment and usually end when treatment ends. Long-term side effects may not go away completely for months or years after treatment; a few may be permanent. A third kind, late effects, occurs at least six months after treatment ends.

See below for the most common side effects of bladder cancer treatment.

HELP FOR SIDE EFFECTS

Following are examples of supportive care for two common side effects.

- **Nausea and vomiting** – Drugs that help prevent and control nausea and vomiting are called antiemetics. A combination of antiemetics may be used, and they may be started before your cancer treatment begins if the treatment is likely to provoke either. Antiemetics must be taken at the specific intervals your doctor prescribes.

  Nondrug techniques also may help – for example, acupuncture or progressive muscle relaxation. In addition, eat several small meals each day, eat a light meal a few hours before (non-surgical) treatment, drink plenty of liquids in small amounts, avoid unpleasant odors, and rest after eating (but don’t lie flat).

- **Fatigue** – Regular exercise (such as walking or yoga) is one of the best ways to help reduce symptoms of fatigue. In addition, ask your doctor for help managing symptoms that may contribute to fatigue, such as pain, nausea, vomiting, and depression. For severe fatigue, your doctor may prescribe a short course of a psychostimulant drug, which can help improve your alertness and raise your energy during the day.

  Other tips: Do only the most important activities, schedule them for times of the day when you feel the most energetic, and ask family and friends for help. Sit down when washing or grooming yourself. Eat a well-balanced diet. Try deep-breathing exercises. Pray or meditate. Enjoy a massage. Take short naps frequently, and try to get eight hours of sleep each night.

A SENSE OF CONTROL

When you talk to your doctor about options for treating your cancer, ask questions about possible side effects and supportive care for them. Knowing about side effects and their treatments will help you feel more in control.

You’ll also recognize side effects sooner, which means you can seek care more quickly. Managing side effects successfully will help you feel better and improve your quality of life, making it more likely that you’ll finish the treatment and increase the possibility of cure.

### MOST COMMON SIDE EFFECTS BASED ON TYPE OF BLADDER CANCER TREATMENT

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Short-term Side Effects</th>
<th>Long-term Side Effects</th>
<th>Late Effects</th>
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<tbody>
<tr>
<td>Transurethral resection of bladder tumor (TURBT)</td>
<td>Pain or discomfort, Bleeding or burning sensation when urinating</td>
<td>Blocked urine flow, Incontinence, Infection</td>
<td>Other sexual side effects</td>
</tr>
<tr>
<td>Cystectomy and urinary diversion</td>
<td>Reaction to anesthesia, Bleeding, Pain, Swelling, Limited activities, Infection</td>
<td>Incontinence, Blocked urine flow, Digestive issues (slow digestion/constipation, diarrhea), Mild anemia, Pouch stones</td>
<td>Scars, Impaired wound healing, Chronic pain, Increased risk of blood clots, Nighttime incontinence, Erectile dysfunction (men)</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>Skin sensitivity (redness, dryness, peeling, itchiness), Anaemia, Hair loss (in treatment area), Nausea and vomiting, Burning sensation while urinating</td>
<td>Frequent urination, Bleeding from the bladder (blood in the urine), Bleeding from rectum, Diarrhea, Fatigue, Easy bruising or bleeding</td>
<td>Erectile dysfunction (men), Fatigue, Dry mouth, Chronic radiation cystitis</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Nausea and vomiting, Neutropenia (which increases risk of infection), Anaemia, Fatigue</td>
<td>Changes in appetite, Hair loss, Mouth sores, Diarrhea, Skin and nail changes</td>
<td>Fatigue, Menopausal symptoms (women), Peripheral neuropathy (nerve problems), Cognitive dysfunction (forgetfulness or trouble concentrating), Cardiomyopathy (heart problems)</td>
</tr>
<tr>
<td>Intravesical therapies (placed into the bladder)</td>
<td>Flu-like symptoms (chills, mild fever, fatigue), Burning feeling in the bladder</td>
<td>Bleeding from the bladder (blood in the urine), Frequent urination, Urinary tract infection (UTI)</td>
<td></td>
</tr>
<tr>
<td>BCG</td>
<td>Muscle aches, Bone pain, Headaches</td>
<td>Difficulty thinking and concentrating, Fatigue, Nausea and vomiting</td>
<td></td>
</tr>
<tr>
<td>Synthetic interferon</td>
<td>Irritation and burning feeling in the bladder</td>
<td>Frequent urination, Urinary tract infection (UTI)</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Dana Caparoso was just 43 years old when she saw the first sign of her bladder cancer: blood in her urine. She thought it was strange so she asked her gynecologist about it. Blood tests and a pelvic ultrasound showed nothing abnormal, so it was attributed to perimenopause. She knew something wasn’t right though and pursued further explanation.

Baby Steps
Lead Survivor through Cancer Journey

After the first round of tests, additional symptoms began to surface: blood on the tissue after going to the bathroom, a feeling of pressure in my bladder without ever being able to fully empty it and lower back pain. I was told it was likely a urinary tract infection or back pain from ovulation – nothing to worry about. But the symptoms persisted, and eventually I went to my primary care physician, who recommended I see a urologist. My first thought was that a urologist is a doctor for my husband, not me. I soon learned that was a misconception. When I went, he performed a urine test and ordered a CT scan. I received a call that evening letting me know I needed to come back the next day. He told me there was a tumor in my bladder and I began to cry. All I could think about was, “What about my children?”

I was in complete denial. I even asked my husband not to tell anyone and we waited to tell our children. I decided to pursue a second opinion and the physician performed a cystoscopy in her office. She even showed me the tumor on the screen. I made an appointment for later that week and went in thinking it was to have the tumor removed. However, as I sat on the operating table, my doctor told me she was only doing a biopsy. The results showed that I had Stage TIIIB bladder cancer that had gone through the fatty layer of my bladder but had not spread any further. One week later, I met with the oncologist who told me I needed to start chemotherapy to shrink the tumor. I started four rounds of combination chemotherapy with cisplatin and gemcitabine. I was tired, a little nauseous and water tasted like metal. Although it was an adjustment, I was thankful the physical side effects weren’t severe.

Emotionally, it was a bit more difficult. Telling my kids was one of the hardest things I’ve ever done. But I sat them down and explained that I was going to fight so that I could be there for them. My husband and my girls became my inspiration and a line from The Shawshank Redemption became suddenly fitting: “Get busy living, or get busy dying.” And I was not done living yet.

About eight weeks after chemo, I had surgery: a radical cystectomy to remove my bladder, a hysterectomy and an oophorectomy – basically any organs where the cancer might spread were removed. To replace my bladder, the surgeon used a part of my colon and intestine to create an internal pouch, called an Indiana pouch. It took about a month to heal and then it took time for the pouch to expand.

My new normal became using a catheter to empty my bladder through a stoma in my belly button. At first, everywhere we went it became about scouting bathrooms and I was catheterizing myself every half hour. I did occasionally have leaks from my stoma, but as a former breastfeeding mother, I realized I could use nursing pads to absorb the leakage. For me, they were the perfect size and pretty absorbent. And I always brought a change of clothes, just in case.

Eventually, I developed a pattern and would catheterize whenever I felt a sense of fullness or at two hours, whichever came first. Over time, I was able to hold it longer and longer. Now, I can go four to six hours and my daily life is as active as ever. I swim and exercise regularly and even play goalie for a recreational soccer team.

In the beginning of my journey, there was fear and self-pity. I asked myself, “Why me?” I came to realize though, “Why not me?” God only gives you what you can handle and although I was absolutely shocked, I knew that I could and that I would get through it. About a month after my surgery, my family and I decided to go on a trip together – my goal was to live my life again and it was about time I started!

A short time after treatment, I decided I wanted to share my story with other women, especially those who may have been misdiagnosed or whose cancer was missed completely. When I reached out, I was introduced to the Bladder Cancer Advocacy Network (BCAN). Their team inspired me and made me truly realize that we are not alone and just how helpful the exchange of information can be. Knowledge is truly powerful. Treatments may not have changed in 20 years, but everyone’s experiences are different and talking about them with other survivors offers invaluable insight into your personal fight against this disease. Do what you have to do to find out what works for you and don’t give up. It gets better, it really does – and every baby step gets easier.
After your bladder cancer treatment concludes, what comes next? Scheduling periodic follow-up visits is a vital step. At these visits, your care team will check your overall health, look for cancer recurrence or a new cancer, and help you manage any long-term concerns. They may also check for late effects, which are similar to side effects, but usually show up later than six months after your treatment ends.

Your doctor initially may want to see you every three to six months. Keeping these appointments is extremely important because people who have had bladder cancer can be at high risk for development of bladder cancer again.

If you still have all or part of your bladder, a typical follow-up visit may include a review of your recent medical history, a physical exam, cystoscopy, urine cytology, imaging tests, and blood tests to make sure the bladder is functioning well and to look for signs of cancer. Your doctor may order urine tumor marker tests to detect specific substances that bladder cancer cells release.

If you're experiencing symptoms such as blood in the urine or painful urination, a urine culture will be done to see if infection is present. An infection can cause the same symptoms as a bladder cancer recurrence.

If your bladder was removed and you have a urinary diversion, you likely will have the same types of tests (except the cystoscopy) to check for changes in kidney function and to look for signs of cancer. Your care team will also check your urinary diversion and help you with problems or concerns you may have with it.

If you develop any health problems between visits, contact your doctor.

DEALING WITH EMOTIONS

Like other cancer survivors, you may face emotional issues both during and after your treatment, including the uncertainty of whether your bladder cancer will return. You may find yourself re-evaluating your life and your relationships or thinking deeply about the end of life. You might be stressed by financial issues caused by your cancer.

No matter what the issue is, reach out for support in ways that work for you. Consider joining a cancer support group or share your concerns with some other group you're comfortable with, such as a church group. Or open up to a relative, friend or counselor.

Talking with other bladder cancer survivors may be especially helpful because they are often coping with the same issues.

TAKING CARE OF YOU

Focus on taking good care of yourself so that you can enjoy life and be ready for the battle if you ever face cancer again. Eat well. Exercise regularly. Limit alcohol consumption to one drink a day if you're a woman or two drinks a day if you're a man. Make a good night's sleep a priority. Although there is no clear evidence that any of these changes will reduce your risk for bladder cancer, they all have health benefits that go beyond cancer prevention.

If you smoke, make a determined effort to quit; bladder cancer is four to seven times more likely to develop in smokers than in nonsmokers. Bladder cancer survivors are also at increased risk of getting cancer of the kidney, ureter, pancreas, larynx, lung, vagina, and prostate, as well as acute myeloid leukemia; some of these are linked to smoking. Don't be discouraged if your first attempt to quit fails – it often takes several tries to succeed.

Keep an eye out for clinical trials that are looking at possible ways to lower the risk of bladder cancer recurrence. Consider joining such a trial if your doctor suggests it.

CREATING A SURVIVORSHIP PLAN

After your cancer treatment, it's a good idea to develop a survivorship plan with your doctor's assistance. It can serve as your roadmap as you move forward in life as a cancer survivor.

Your survivorship plan should include your medical history, contact information for your cancer care team, details of your cancer diagnosis and treatment, information on your risk for late effects and cancer recurrence and/or second cancers, your schedule of follow-up care visits, and information on healthy living (for example, a dietitian's healthy eating advice for you as a bladder cancer survivor). Your survivorship plan also could include your estate plan, as well as a list of resources for future reference in case you need assistance.

CHANGING DOCTORS

At some point, you may stop seeing your cancer team and return to your primary care physician, perhaps because it's your preference or because your health insurance requires it. Or you may move and have to start over with a new doctor who doesn't know anything about you or your medical history.

In either case, it's important to share details of your cancer diagnosis and treatment. Your survivorship plan will have all of that information in one place, making it easy to provide this information to your new doctor.

ADDITIONAL RESOURCES

- American Cancer Society: www.cancer.org/cancer/bladdercancer/index
- American Society of Clinical Oncology: www.cancer.net
- Bladder Cancer Advocacy Network: www.bcan.org
- Bloch Cancer Hotline: 800-433-0464
- CancerCare: www.cancercare.org/diagnosis/bladder_cancer
- Free support from oncology social workers
- Patient Resource: www.patientresource.com/
  Patient_Matching_Service.aspx
- PatientResource.com
FINANCIAL RESOURCES

BASIC LIVING EXPENSES
Brenda Mehling Cancer Fund (patients 18-40) ........................................ www.bmcf.net, 661-310-7940
Bringing Hope Home ........................................................................ www.bringinghopehome.org, 484-580-8395
The CHAIN Fund Inc. ........................................................................ www.thechainfund.com, 203-691-5955
Cleaning for a Reason (free house cleaning service) ... www.cleaningforareason.org, 877-337-3348
Family Reach Foundation ................................................................ www.familyreach.org, 973-394-1411
Hugs and Kisses ................................................................................ www.hugsandkissesinc.org, 561-819-9471
Life Beyond Cancer Foundation ....................................................... www.lifebeyondcancer.com, 281-791-7549
Rise Above It Fund Inc. (youth, young adults) ...................................... www.raibenefits.org
The Simple Dollar ............................................................................ www.thesimpledollar.com/category/insurance
Stupid Cancer .................................................................................. www.stupidcancer.org, 877-735-4673
Team Continuum ............................................................................... www.teamentrium.com, 646-589-5619
Zichron Shloime Refuah Fund ............................................................. www.zsf.org, 718-GET-WELL

CHILD CARE EXPENSES
AVON Foundation for Women .............................................................. www.avonfoundation.org, 866-505-AVON
The Bone Marrow Foundation ............................................................ www.bonemarrow.org, 800-385-1336
Brenda Mehling Cancer Fund (patients 18-40) ...................................... www.bmcf.net, 661-310-7940
CancerCare ........................................................................................ www.cancercare.org, 800-813-HOPE
Family Reach Foundation ................................................................ www.familyreach.org, 973-394-1411
Stupid Cancer .................................................................................. www.stupidcancer.org, 877-735-4673

FINANCIAL ASSISTANCE
American Cancer Society ..................................................................... www.cancer.org
American Kidney Fund ...................................................................... www.kidneyfund.org
BrentsCheckUp .............................................................................. www.brentscheckup.org
Bringing Hope Home ....................................................................... www.bringinghopehome.org
CancerCare ........................................................................................ www.cancercare.org/financial
Cancer Financial Assistance Coalition ................................................ www.cancerfa.org
The CHAIN Fund Inc. ........................................................................ www.thechainfund.com
HealthWell Foundation ...................................................................... www.healthwellfoundation.org
Hope Lodge .................................................................................... www.hope.org/treatment/supportprogramsservices/hopelodge
LIVESTRONG Foundation ................................................................ www.livestrong.org
Medicare ........................................................................................ www.medicare.gov
NeedyMeds ..................................................................................... www.needymeds.com
Partnership for Prescription Assistance .............................................. www.pppar.org
Patient Advocate Foundation ............................................................. www.patientadvocate.org
Patient Services Inc ......................................................................... www.patientservicesinc.org
The Paws for Pauly Foundation Inc. ..................................................... www.pinstforpauly.org
RxAssist ......................................................................................... www.rxassist.org
RxHope ............................................................................................ www.rxhope.org
Social Security Administration ........................................................ www.ssa.gov
Social Security Disability Resource Center ........................................ www.ssdr.com
State Health Insurance Assistance Programs .................................... www.shipacon.org
Stupid Cancer .................................................................................. www.stupidcancer.org

GOVERNMENT ASSISTANCE
Administration on Aging ................................................................. www.aoa.gov, 202-401-4634
Benefits.gov .................................................................................... www.benefits.gov, 800-FED-INFO
Centers for Medicare & Medicaid Services ........................................ www.cms.gov, 800-MEDICARE
Hill-Burton Program .......................................................................... www.hrsa.gov/gethealthcare/affordable/hillburton, 800-638-0742
Legal Services Corporation ............................................................... www.lsc.gov, 202-295-1500
Medicare Rights Center .................................................................... www.medicarerights.org, 800-333-4114
Social Security Administration ........................................................... www.ssa.gov, 800-772-1213
Social Security Disability Resource Center ........................................ www.ssdr.com
State Health Insurance Assistance Programs .................................... www.shipacon.org
U.S. Department of Veterans Affairs .................................................... www.va.gov/health/index.asp

HOME HEALTH CARE EXPENSES
AVON Foundation for Women .............................................................. www.avonfoundation.org, 866-505-AVON
Brenda Mehling Cancer Fund (patients 18-40) ...................................... www.bmcf.net, 661-310-7940
CancerCare ........................................................................................ www.cancercare.org, 800-813-HOPE
NeedyMeds (links to assistance programs) ........................................ www.needymeds.org, 800-503-6897
Stupid Cancer .................................................................................. www.stupidcancer.org, 877-735-4673

HOUSING DURING TREATMENT EXPENSES
Brenda Mehling Cancer Fund (patients 18-40) ...................................... www.bmcf.net, 661-310-7940
Fisher House (military families) ......................................................... www.fishhouser.org, 888-294-8560
Hope Lodge .................................................................................... www.hope.org/treatment/supportprogramsservices/hopelodge/index, 800-227-2945

LEGAL ISSUES
Disability Rights Legal Center ............................................................ www.disabilityrightslegalcenter.org, 888-999-3752
Legal Services Corporation ............................................................... www.lsc.gov, 202-295-1500
National Health Law Program (links to assistance programs) ........ www.healthlaw.org, 202-289-7661
Social Security Disability Resource Center ........................................ www.ssdr.com

PRESCRIPTION EXPENSES
American Cancer Society ................................................................. www.cancer.org, 800-ACS-2345
Brenda Mehling Cancer Fund (patients 18-40) ...................................... www.bmcf.net, 661-310-7940
CancerCare Copayment Assistance Foundation ............................. www.cancercarecopay.com, 866-552-6729
Cancer Financial Assistance Coalition ............................................... www.cancerfa.org
The CHAIN Fund Inc. ........................................................................ www.thechainfund.com, 203-691-5955
Foundation for Health Coverage Education ........................................ www.coverageforall.org
Good Days ...................................................................................... www.gooddaysfrommcf.org, 877-986-7233
HealthWell Foundation ...................................................................... www.healthwellfoundation.org, 800-675-9416
National Organization for Rare Disorders ......................................... www.rarediseases.org, 203-744-0100
NeedyMeds (links to assistance programs) ........................................ www.needymeds.org, 800-503-6897
Partnership for Prescription Assistance ............................................ www.pppar.org, 888-4PPA-NOW
Patient Access Network Foundation ................................................ www.panfoundation.org, 866-316-PANF
Patient Advocate Foundation Co-Pay Relief ...................................... www.copays.org, 888-512-3861
Patient Services Inc .......................................................................... www.patientservicesinc.org, 800-366-7741
Rise Above It Fund .......................................................................... www.raibenefit.org
RxAssist ......................................................................................... www.rxassist.org
RxHope ............................................................................................ www.rxhope.org, 877-267-0517
RxOutreach ....................................................................................... www.rxoutreach.com, 888-786-1204
Stupid Cancer .................................................................................. www.stupidcancer.org, 877-735-4673
Together Rx Access .......................................................................... www.togetherrxaccess.com, 800-444-4106

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS
Angen Assist ..................................................................................... www.angenassist.com, 888-427-7478
Bristol-Myers Squibb ........................................................................ www.bms.com/products/Pages/applications.aspx, 888-861-0048
Celgene Patient Support .................................................................... www.celgenepatientsupport.com, 800-931-9891
Endo Patient Assistance Program for Valstar ..................................... www.endopatientassist.org, 888-429-9418
Genentech Access Solutions ............................................................. www.genentech-access.com, 888-429-9418
Janssen Prescription Assistance ......................................................... www.janssenprescriptionassistance.com
Johnson & Johnson Patient Assistance, Inc. ....................................... www.jjpa.org, 855-622-6727
Lilly PatientOne ................................................................................ www.lillypatiente.com, 866-472-9883
Merci Helps ...................................................................................... www.mercihelps.com, 800-727-5400
Novartis Patient Assistance Now ...................................................... www.patientassistance.com, 888-254-5368
Sanofi Patient Connection ............................................................... www.visitsanofline.com, 888-847-4877
Teva Oncology Core Reimbursement Assistance & Support ............ www.tevacoore.com, 888-587-3263

TRANSPORTATION & TRAVEL RESOURCES
The Air Care Alliance ....................................................................... www.aircarealliance.org, 888-260-9707
Air Charity Network .......................................................................... www.aircharitynetwork.org, 877-621-7177
American Cancer Society (Road to Recovery) .................................... www.cancer.org, 800-ACS-2345
Angel Airline Samaritans ................................................................. www.angelairlinesamaritans.org, 800-296-1217
Angel Airline for Cancer Patients ...................................................... www.angelairlinesforcancerpatients.org, 800-296-1217
Angel Flight Central .......................................................................... www.angelflightcentral.org, 866-569-9494
Brenda Mehling Cancer Fund (patients 18-40) ...................................... www.bmcf.net, 661-310-7940
CancerCare ........................................................................................ www.cancercare.org, 800-813-HOPE
Cha LifeLine ..................................................................................... www.chalifeline.org
Corporate Angel Network ................................................................. www.corpangelnetwork.com, 914-328-1313
Family Reach Foundation ................................................................. www.familyreach.org, 973-394-1411
Hospitality Homes .......................................................................... www.hosp.org, 888-595-4678
Joe’s House ....................................................................................... www.joeshouse.org, 877-JOESHOU
Lifeline Pilots .................................................................................... www.lifelinepilots.org, 800-822-7972
LIVESTRONG Foundation ................................................................ www.livestrong.org
Merry Medical Angels ....................................................................... www.merrymedical.org
National Patient Travel Center ......................................................... www.patienttravel.org, 800-296-1217
Operation Liftoff .............................................................................. www.operationliftoff.com
Patient Access Network Foundation ............................................... www.panfoundation.org, 888-316-7263
Patient AirLift Services ..................................................................... www.patientairlift.com, 631-694-7257
Rise Above It Fund (youth, young adults) ........................................ www.raibenefit.org
Stupid Cancer .................................................................................. www.stupidcancer.org, 877-735-4673
Veterans Airlift Command ............................................................... www.veteransairlift.org, 952-582-2911
Zichron Shloime Refuah Fund ............................................................ www.zsf.org, 718-GET-WELL
BLADDERS CANCER
Action on Bladder Cancer .................................................. www.actiononbladdercancer.org
American Bladder Cancer Society ........................................ www.abcs.org
Bladder Cancer Advocacy Network ..................................... www.bcan.org
Bladder Cancer Canada ........................................................ www.bladdercancer.ca
Fight Bladder Cancer ............................................................. www.fightbladdercancer.org.uk
United Ostomy Associations of America, Inc. ....................... www.ostomy.org

CANCER EDUCATION
Academy of Oncology Nurse Navigators .............................. www.aonnc.org
American Cancer Society .................................................... www.cancer.org
American Society of Clinical Oncology ............................... www.asco.org
Association of Community Cancer Centers .......................... www.accc-cancer.org
CANCER101 ........................................................................ www.cancer101.org
CancerCare ............................................................................. www.cancercare.org
CancerGuide ........................................................................... www.cancerguide.org
Centers for Disease Control and Prevention (CDC) ............... www.cdc.gov
The Gathering Place ............................................................... www.touchbycancer.org
Get Palliative Care ................................................................. www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE) .... www.cancergrace.org
The Hope Light Foundation ................................................... www.hopelightproject.com
LIVESTRONG Foundation ..................................................... www.livestrong.org
National Cancer Institute ..................................................... www.cancer.gov
National Comprehensive Cancer Network (NCCN) .............. www.nccn.org
National LGBT Cancer Network ......................................... http://cancer-network.org
Oncology Nursing Society .................................................... www ons.org
PearlPoint Cancer Support .................................................... www.pearlpoint.org
Pine Street Foundation .......................................................... www.pinestreetfoundation.org
R.A. Bloch Cancer Foundation, Inc. ........................................ www.blochcancer.org
Scott Hamilton CARES Foundation ...................................... www.scottcares.org
Wellness Place ........................................................................ www.wellnessplace.org

CAREGIVERS & SUPPORT
4th Angel Mentoring Program .............................................. www.4thangel.org
BCAN Online Community .................................................. www.bcan.org/learn/find-support/bcan-online-community
Bladder Cancer Advocacy Network ..................................... www.bcan.org
Bladder Cancer Hotline ....................................................... 800-433-0684
Cancer Action ................................................................. www.canceractiontc.org
Cancer and Careers ............................................................ www.cancerandcareers.org
CancerCare ............................................................................. www.cancercare.org
Cancer Connection ............................................................... www.thecancerconnection.org
Cancer Hope Network ........................................................ www.cancerhopeenetwork.org
Cancer Information and Counseling Line .............................. 800-525-3777
Cancer Really Sucks! ............................................................. www.cancerreallysucks.com
Cancer Support Community ................................................ www.cancersupportcommunity.org
Cancer Support Community-Open to Options counseling program .................................................. 888-793-9355
Cancer Survivors Network ................................................... http://cancerrc.org
Cancer Wellness Center ....................................................... www.cancerwellness.org
Caregiver Action Network ................................................... www.caregiveraction.org
CaringBridge .......................................................................... www.caringbridge.org
Center to Advance Palliative Care ........................................ www.capc.org
Cleaning For A Reason ........................................................ www.cleaningforexreason.com
Cooking with Cancer ........................................................... www.cookingwithcancer.com
Cuddle My Kids ..................................................................... www.cuddlemykids.org
Family Caregiver Alliance ................................................... www.caregiver.org
Fighting Chance ...................................................................... www.fightingchance.org
Friends for Life Cancer Support Network ............................. www.friend4life.org
The Gathering Place ............................................................. www.touchedbycancer.org
Guam Cancer Care ............................................................... http://guamcancer.org
Guide Posts of Strength Inc. .................................................. www.cancergo.org
The Hope Light Foundation ................................................... www.hopelightproject.com
I Can Cope ............................................................................ www.cancer.org/treatment/supportprograms/services/onlinecommunities/participateinacancereducationclass/cancereponline
Imeman Angels ...................................................................... www.imemanangels.org
The LGBT Cancer Project - Out With Cancer ....................... www.lgbtcan.org
LIVESTRONG Foundation ..................................................... www.livestrong.org
LivingWell Cancer Resource Center ..................................... www.livingwelllic.org
Lotsa Helping Hands .............................................................. www.lotsahelpinghands.com

CLINICAL TRIALS
ACT (About Clinical Trials) .................................................... www.act.org
Bladder Cancer Advocacy Network ..................................... www.bcan.org
Center for Information and Study on Clinical Research Participation ................................ www.searchclinicaltrials.org
CenterWatch ................................................................. www.centerwatch.com
Coalition of Cancer Cooperative Groups ............................ www.canceralliance.com
LIVESTRONG Foundation ..................................................... www.livestrong.org/we-can-help/planning-medical-care/considering-clinical-trials
MolecularMatch ................................................................. www.molecularmatch.com
My Clinical Trial Locator ..................................................... http://myclinicaltriallocator.com
National Cancer Institute .................................................... www.cancer.gov
National Institutes of Health ................................................ www.ninds.nih.gov
National Institutes of Health ................................................ www.nci.nih.gov
TrialCheck ................................................................. www.trialcheck.com

COMPLEMENTARY PRODUCTS & ALTERNATIVE MEDICINE
Believe Big ................................................................. www.believebig.org
Kansas City Healing Project ................................................ www.kansascityhealingproject.org
OncoLink ................................................................................ www.oncologist.com
PearlPoint Cancer Support ................................................ www.pearlpoint.org

PAIN MANAGEMENT
American Chronic Pain Association ...................................... www.theacha.org
Cancer Pain Research Consortium ........................................ www.cancerpainresearch.org
LIVESTRONG Foundation ..................................................... www.livestrong.org
The Resource Center of the Alliance of State Pain Initiatives ...... www.rsc.org
U.S. Pain Foundation ............................................................. www.uspain.org

PATIENT ADVOCACY
American Cancer Society Cancer Action Network Inc. ........... www.acscan.org
Bladder Cancer Advocacy Network ..................................... www.bcan.org
Cancer Legal Resource Center ............................................ www.cancerlegalresource.com
Friend for Life Cancer Support Network ............................. www.friend4life.org
LIVESTRONG Foundation ..................................................... www.livestrong.org
National Coalition for Cancer Survivorship ......................... www.cancervictory.org
Patient Advocacy Foundation ............................................. www.patientadvocate.org

RESEARCH
American Association for Cancer Research ........................ www.aacr.org
American Institute for Cancer Research ............................... www.aicr.org
Bladder Cancer Advocacy Network ..................................... www.bcan.org
Cancer Research Institute ..................................................... www.cancercr.org
The Chemotherapy Foundation ........................................... www.chemotherapyfoundation.org
Friends of Cancer Research ................................................ www.focr.org
International Cancer Advocacy Network ............................... www.ascan.org
International Cancer Alliance for Research and Education .......... www.icare.org
Pine Street Foundation ........................................................ www.pinestreetfoundation.org
Prevent Cancer Foundation ............................................... www.preventcancer.org
Research Advocacy Network ............................................... www.reserachadvocacy.org
Scott Hamilton CARES Foundation .................................... www.scottcares.org
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